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Beyond a Boundary – Conceptualising and Measuring Multiple Health Conditions in the Scottish Population

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Declaration

I declare that this thesis has been completed by me, is my own work, and has not been submitted for any other degree or professional qualification.

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Abstract

The concurrent experience of multiple health conditions (often termed multimorbidity) has become an important issue in recent years. Most research on this topic uses clinical data (e.g. GP or hospital records) that lack important socio-contextual information about the lives of people with multiple conditions. Population health surveys can help to overcome these limitations, but identifying people who have multiple conditions is problematic. Decisions need to be taken regarding what is meant by a condition, which ones should be included, and how multiple should be defined. These decisions tend to be based on what data are available, rather than on any universal inclusion criteria or theoretical underpinnings.

This thesis used an approach informed by sociological theory and principles drawn from critical realist philosophy to estimate the prevalence of multiple conditions among adults (16+) in the general population, using data from the 1998 and 2008-2011 Scottish Health Surveys. It explicitly acknowledged the multiple, contested and constructed nature of health, illness and diagnosis; the limits of empirical enquiry; and the need to approach concepts such as multiple conditions critically. To support the decision-making process, longitudinal analyses of mortality were used to examine the impact of including various contested conditions on people's long-term chance of survival (if there was no evidence of impact then the definition was rejected). The final measure of multiple conditions arrived at suggested that 24.9% of adults had multiple conditions (compared with 17.2% using the survey's original, unadjusted, measure). This measure was then used to explore how this status related to people's wellbeing, which helped to highlight importance differences in experiences.

Among adults with multiple conditions, 33.5% of those in the most deprived areas had low wellbeing compared with 13.5% of those in the least deprived areas. Low wellbeing was also higher among people with multiple conditions aged under 65 than those aged 65 and over, especially for those living in areas of high deprivation. There was some evidence that having multiple conditions and additional vulnerabilities (e.g. psychological distress, living in a deprived area, having activity limitations) before the age of 55 increased people's risk of mortality, which might result in older populations

appearing to have better wellbeing due to less healthy people not reaching old age. Working-age people with multiple conditions were also more likely than people of the same age with no conditions to be economically inactive, to not live in an owner-occupied property, and not have a co-resident partner. All of which suggest that poor health at younger ages limits access to the social and economic norms enjoyed by most people.

The approach adopted arguably helped to avoid over-classifying largely healthy people as having multiple conditions, while still ensuring that people's own perspectives on their health were not under-privileged with respect to more traditional biomedically-focused approaches. However, it was also clear that the experiences of adults with multiple conditions are highly varied, and in particular, socially stratified. This heterogeneity has implications for research in this field, as well as clinical practice and public health policy. Recommendations for better reflecting this diversity in future studies included collecting more measures of functional capacity, aspirations, illness experiences, and social stressors (such as financial insecurity).

Lay summary

Health services are usually organised around single conditions (e.g. hospital doctors who specialise in one condition or area of the body). Treatments are often also designed with one condition in mind. However, many people, especially as they get older, will end up with more than one diagnosed condition. Having multiple conditions often brings considerable stress.

This research was designed to find out how many people aged 16 and over in Scotland have more than one long-term health condition. This information can help the NHS to plan its services. It can also be used to see what kinds of people are more likely than others to have multiple conditions, and to see what affect this has on quality of life.

This project used a survey conducted in people's homes that asked a range of questions about conditions and other health problems. There are many different ways to think about health, for example some people say that high blood pressure is a disease, but not everyone does. This project put together lots of different pieces of information about people's health to provide a more complete picture of who had more than one condition. It then explored how people's conditions affected their wider wellbeing – e.g. their happiness, confidence and enjoyment of life.

The main results were that, as a group, people with more than one condition had lower levels of wellbeing than healthier people, and in some cases, people with multiple conditions died at a younger age than average. However, there were also lots of differences within this group of people with multiple conditions. For example, having low wellbeing was much more common in people under 65 with multiple conditions than it was for people aged 65 and over. It was also more common for people with multiple conditions living in the more deprived areas in Scotland than those living in the better off areas. People aged under 65 with multiple conditions were also less likely than healthy people of the same age to own their own home, live with a partner, or have a job. These experiences might help explain why this group also had low levels of wellbeing. In future, it would be useful to find out more about the different way that having multiple conditions affects people's lives.

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List of Acronyms & Abbreviations

ADHD	Attention Deficit Hyperactivity Disorder
BMI	Body Mass Index (height in metres, divided by squared weight in kilograms)
BNF	British National Formulary
CI	Confidence interval
CIS-R	Clinical Interview Schedule - Revised
CPHR	Cox Proportional Hazard Ratio
CVD	Cardio-vascular disease
DBP	Diastolic blood pressure
DSM	Diagnostic and Statistical Manual (of the American Psychological Association)
GHQ12	General Health Questionnaire 12
HbA1C	Glycated haemoglobin
HES	Health examination survey
HIS	Health interview survey
HRQoL	Health-related quality of life
HSE	Health Survey for England
ICD	International Classification of Disease
IRCM	International Research Community on Multimorbidity
LTC	Long-term condition
MAOI	Monoamine-oxidase inhibitor
MI	Myocardial infarction
NCD	Non-communicable disease
NICE	National Institute for Health and Care Excellence
NHS	National Health Service
OHP	Other health problem
OR	Odds ratio
QOF	Quality Outcomes Framework
SBP	Systolic blood pressure
SD	Standard deviation
SES	Socio-economic status
SHeS	Scottish Health Survey
SIGN	Scottish Intercollegiate Guidelines Network
SIMD	Scottish Index of Multiple Deprivation
SMR	Scottish Morbidity Register
SSRI	Selective serotonin re-uptake inhibitor
SWEWMBS	Short Warwick-Edinburgh Mental Wellbeing Scale
UDH	Undeclared hypertension
WEMWBS	Warwick-Edinburgh Mental Wellbeing Scale
WHO	World Health Organisation

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Chapter 1 Introduction

Introduction

This thesis presents analyses of the proportion of adults in Scotland living with multiple long-term health conditions, and explores some of the challenges this group of people face. Scotland's poor health outcomes, relative to the rest of the UK, and most of Europe, have long been a subject of considerable interest to researchers, clinicians and policy makers (Leyland et al. 2007; Whyte & Ajetunmobi 2012). A vast body of work designed to help account for the comparatively high levels of mortality in Scotland – and Glasgow in particular – is currently being synthesised to try and address the question of why this finding persists even when factors such as deprivation have seemingly been taken into account (ScotPHO 2015a). The link between Scotland's poor health and wider inequalities has arguably attracted a new level of political saliency in recent times, as illustrated by social media commentary following the vote against Scottish independence in the referendum on 18 September 2014 highlighting the inverse correlation between support for independence and life expectancy, including Tweets from one of Scotland's former Chief Medical Officers (The Sunday Post 2014).

Beyond mortality, Scotland's levels of healthy life expectancy at birth (projected years lived in a healthy state) are lower than in England and the rest of Europe for males, though appear to be better for females (ScotPHO 2015b). A boy born in Scotland in 2014 would be expected to live for an average of 77.4 years, with 60.3 of those years in good health, while the corresponding figures for a girl are 81.4 and 62.6, respectively (ScotPHO 2015b), with chronic non-communicable diseases (NCDs) accounting for much of these gaps between total and healthy life expectancy. Considerable inequalities in this outcome also exist. The most recently published estimates, based on 2009-2013 data, show gaps in healthy life expectancy at birth of 18.1 years (male) and 16.7 years (female) between those in the least and most deprived area quintiles (ScotPHO 2015b).

The need to understand more about the lives of the people in Scotland with the highest NCD burden, that is, people with multiple long-term conditions, in order to

improve the quality and, hopefully, duration of their lives, as well as to prevent future cohorts experiencing similarly poor outcomes should, therefore, be abundantly clear.

Context

The recognition that people often experience multiple concurrent long-term health conditions (typically termed multimorbidity) has become an important focus of health services research, epidemiology, clinical practice and public health policy in recent years. Despite its fairly recent emergence as a concept of interest, a sizeable body of research has been generated to date, highlighting a number of key concerns. These concerns include the fact that multimorbidity has a demonstrable association with negative patient outcomes; that it challenges most of the systems and guidelines currently in place within health systems, due to their being developed at a time when single disease frameworks were predominant; and the increasing costs attributed to treating people with multimorbidity as the population ages (in high income countries, at least). Much of the evidence within this field is based on data that privilege clinically-oriented perspectives on health and illness (e.g. primary care or hospital records). Such sources often lack important socio-contextual information about the lives of people who have multiple conditions, including their own reflections of their health conditions and their impact. Thus the potential to use such evidence to help improve outcomes by identifying key intervention opportunities can sometimes be constrained by the nature of the data on which it is based.

Population health surveys can help to overcome these limitations, due to the wide range of information they can collect about people's conditions as well as their wider life experiences and circumstances. However, reports of conditions that are based solely on information gathered directly from members of the public are often treated with scepticism, due to their tendency to underestimate prevalence (when compared with figures drawn from medical records). In addition to this problem, a perhaps greater (but not necessarily insurmountable) issue is the fact that consensus about how to define and measure multimorbidity is far from universal in the literature. Debates surround the kinds of underlying conditions that should be included in any

definition, the appropriate threshold for establishing the existence of multiplicity, and what scope there is to integrate aspects such as condition severity into any measures.

This thesis uses detailed analyses of the health conditions data collected in the 2008-2011 Scottish Health Surveys (the principal survey source of population-level public health data in Scotland), via a series of open and closed questions, to develop a measure of multiple conditions. The impetus for this stemmed from work I carried out in spring 2013 when specifying the contents for a new chapter on long-term conditions to be included in the 2012 survey's report (Gray & Leyland 2013).[1] This topic had previously been reported alongside self-rated health, wellbeing and psychological distress, but the Scottish Government's increasing interest in long-term conditions means that this topic is now reported in its own right when space permits. A prevalence estimate of *multiple* long-term conditions had been included in previous reports, but using a fairly crude measure based on only one set of the survey's conditions data, aggregated to reflect International Classification of Disease (ICD) chapter headings, and therefore potentially losing details about multiple conditions in the process (Chapters 3 and 5 provide an overview of all available data). I was tasked at that time with investigating whether the data could be used to provide a better measure of multiple long-term conditions. The pressures of tight delivery schedules within a contract research environment often lead to decisions about measures such as this needing to be taken quite hastily, but the more I explored the matter, the clearer it became that the task required more than the scant consideration that would have been possible at that time. The question of producing a quick measure for that year's report was abandoned, and this thesis now represents the culmination of the more detailed work that then followed to address this issue more thoughtfully and thoroughly.

The process took account of the various conceptual debates evident in the multiple conditions literature (highlighted in Chapter 2). However, the process adopted also followed an approach that drew heavily on the broader theoretical perspectives offered by sociological approaches to the meaning, classification and diagnosis of conditions,

[1] I was Director of the 2008-2011 Scottish Health Surveys, and have been providing advice on the 2012-2015 surveys as an independent consultant, alongside my PhD study.

as well as insights about medicalisation, overdiagnosis and illness experiences. These perspectives were integrated with longitudinal analyses of mortality to help inform a series of decisions about what underlying conditions and risks should be included in the measure of multiple conditions.

The kinds of issues considered included hypertension (more than two-thirds of people with hypertension do not declare it unless prompted) and obesity (which is almost never self-reported), both of which revealed insights about the incongruence between clinical and lay perspectives, the nature of illness experiences, and a possible rejection of the increasing medicalisation of disease risks. Similarly, symptom and medication data suggested a high degree of under-reporting of mental health conditions, but, the consequences of potentially medicalising symptoms of normal distress (which are collected in the survey and are often used in similar analyses as markers of potentially diagnosable conditions) had to be balanced against the risk of losing important contextual insights.

The overarching aim was the development of a multiple conditions measure that reflects, as far as possible, the lived experiences of people with those conditions. Creating such a measure helped move the survey away from its single disease-focus origins and now aligns it more closely with this increasingly important, arguably more holistic, conceptualisation of health experiences. A further set of analyses, using the newly created measure to explore the association between multiple conditions and low wellbeing, was used to help to provide further insights about the distinctiveness – or otherwise – of people with multiple conditions, and thus shape its conceptualisation as a singular entity.

What is already known about multimorbidity in Scotland?

As already noted, and as the literature review in Chapter 2 will expand on in far more detail, the epidemiology of multimorbidity has been extensively studied in recent years (Fortin et al. 2012; Huntley et al. 2012a; Violan et al. 2014). This is particularly the case in Scotland, thanks to the availability of an extensive primary care dataset (generated in 2007) covering over a third of the country (Barnett et al. 2012; McLean et al. 2014). Their key findings include the fact that, from the age of 55, having

multiple conditions is more common than having just one, and that from the age of 65, the majority of people have multiple conditions (McLean et al. 2014). The social distribution of this outcome is not, however, uniform. Notable inequalities are evident by level of area deprivation, particularly for those of working-age, and among people whose conditions include a diagnosed mental illness, to the extent that people from the most deprived 10% of areas in Scotland can be seen to experience the onset of multiple conditions around 10-15 years before those from the least deprived areas (Barnett et al. 2012).

In addition to these studies of prevalence, qualitative work with clinicians (O'Brien et al. 2011) and patients (O'Brien et al. 2014) in one of the most deprived 15% of areas in the West of Scotland has demonstrated the complexity of providing care to this group of people, and the challenges they face managing their conditions alongside their everyday lives. Most significantly, this work reveals the extent of the mental distress that accompanies living with multiple conditions in conjunction with high levels of social deprivation. An analysis of multiple conditions and health-related quality of life (HRQoL) using the 2003 Scottish Health Survey confirms this point (Lawson et al. 2013).

What will this analysis address and add?

The principal aim of the work presented in this thesis is to:

- Quantify the experiences of adults living with multiple conditions in Scotland using the Scottish Health Survey.

By answering the following questions:

- Does the Scottish Health Survey correctly identify people with multiple conditions?
    - And if not, who is missing?
- How do different definitions of multiple conditions affect its prevalence in the population, and across sub-groups?
- How do experiences of people living with multiple conditions vary in the population?

At the very least, the development of a more comprehensive measure of multiple conditions will ensure that this key source of population health data (the Scottish Health Survey) is able to meet increasing demands from policy makers and health service planners for information about the characteristics, nature and long-term outcomes for people with multiple conditions. While the data collected in population surveys differ in their nature from those collected in primary care settings, which results in some notable differences between their prevalence estimates (as illustrated in Chapter 5), the wider availability and breadth of topics covered in this survey means that it has the potential to address important information gaps related to multiple conditions that the data analysed by Barnett et al. (2012) could not. For example, the extent to which multiple conditions cluster with known disease risks and other important contextual factors (such as individual-level measures of socio-economic status), or the extent of their variation across time. These outcomes are beyond the scope of this thesis, but serve to illustrate the wider analytical opportunities that would be afforded by having a comprehensive measure of multiple conditions. Similarly, their association with outcomes such as quality of life and, indeed, quantity of life (via the mortality records to which most participants' data are linked) can also be explored (Chapters 5 and 6 present some results of such analyses). But, more than this, these data have the potential to identify potential mechanisms that could increase understanding of the ways in which having multiple conditions impact on people's lives (some examples of these are provided in Chapter 6).

In addition, the development of this new measure of multiple conditions drew on an extensive review of the conditions information collected in the survey (as reported in Chapter 5), from which a series of recommendations could also be made about potential improvements to the survey questions (outlined in Chapter 7).

Finally, the approach adopted in this thesis is novel because, unlike traditional empirical analyses, the methodology adopted explicitly acknowledges the multiple, contested and constructed nature of health, illness and diagnosis; the limits of empirical enquiry; and the problems associated with conceptualising a phenomenon such as multimorbidity uncritically. The work presented here therefore also provides

an opportunity to explore the extent to which attempts to integrate different theoretical perspectives can add value to analyses of quantitative data.

Terminology

Before presenting an overview of the remaining contents of this thesis, a note on terminology is necessary. Most research and clinical practice on this topic employs the term *multimorbidity* to describe the state of having multiple conditions. The work presented in this thesis consciously departs from this terminology and instead uses the term *multiple conditions* rather than multimorbidity, wherever possible. There are a number of reasons for this. The overriding reason is my desire to reject this rather clinically-oriented label in favour of one that gets closer to a form of language that the majority of the population would be likely to identify with. A second reason is my wish to avoid turning the experience of living with multiple conditions into an artificially singular state of being. The language used to describe individual conditions can unhelpfully turn people into their illness ("an epileptic / a diabetic"), whereas terminology that describes conditions as entities that people *have* ("a person with epilepsy / with diabetes") retains the agency of the person concerned. In much the same way, I would argue, the term "multimorbid" describes a state of being, whereas "multiple conditions" describes a state of having. To ask what is the prevalence of multimorbidity, or to ask what characterises the multimorbid, therefore implies a level of reductionism, abstraction from the particular, and perhaps even a level of certainty about the ontological status of multiple conditions, that I am uncomfortable with. It has proved impossible to avoid all uses of the term multimorbidity, and it has been retained in much of the discussion of existing literature because it is describing work that uses that term. However, in discussions of my work's aims, methods and results, multiple conditions is the favoured term.

This concern for language might seem unusual for a quantitatively-based analysis ultimately designed to yield numbers. However, as I hope to demonstrate, by using insights from the worlds of sociology to inform epidemiological practice - one aspect of which is a heightened attention to the power of language and labelling - it is possible

to bridge, in part, the gap that lies between the act of quantifying lived experiences and the reality of living them.

Overview of this thesis

The rest of this thesis is structured as follows:

- Chapter 2 presents a review of the literature on multiple conditions, including a consideration of its historical emergence as well as a summary of the main points of consensus emerging from that body of work.
- Chapter 3 outlines the methods and methodology adopted for this thesis. It begins with a detailed description of the data source (the Scottish Health Survey), the health conditions measures contained within it, and a review of its key strengths and weaknesses. Towards the end there is a more detailed discussion of the ontological and epistemological underpinnings of the overall approach, followed by an overview of how this was operationalised.
- Chapter 4 provides a detailed review of the theoretical insights derived from the sociological literature that have been included in this work. As noted above, these include aspects related to the meaning, classification and diagnosis of conditions, medicalisation, overdiagnosis and illness experiences. It ends with two case studies (of obesity and psychological distress) that are intended to illustrate how these insights were used to guide decisions about what conditions to include in the measure of multiple conditions.
- Chapter 5 presents the results of the various steps that were undertaken in order to derive the new measure of multiple conditions. For each set of considerations, the key issues needing to be resolved are outlined, the methods employed to resolve them are described and the results presented, with the resulting decision summarised before moving on. The new measure of multiple conditions arrived at via this process is then presented and its impact on overall prevalence estimates of multiple conditions, and on the social patterning of this outcome, are then highlighted. Finally, comparisons are made with existing primary care data sources.

- Chapter 6 takes the measure of multiple conditions arrived at in Chapter 5 and explores its association with low wellbeing. The chapter has two aims. The first is to extend some of the previous analyses of multiple conditions and wellbeing reported in the literature to uncover potential mechanisms that might help account for its patterning by age and deprivation level. Secondly, it considers the extent to which the experiences of people with multiple conditions are distinct from those with one condition or none, with a view to using this information to help inform the conceptualisation of this phenomenon.
- Chapter 7 discusses the results presented in Chapters 5 and 6. It starts by focusing on the question of measurement, chiefly drawing on Chapter 5's results, and ends with some recommendations for how the newly defined measure should be taken forward, and how the survey could be amended to make the data collected more effective and/or efficient. It then considers the arguably trickier issue of conceptualisation by taking the wellbeing results from Chapter 6 and asking in what ways does grouping people according to the number of conditions they have increase understanding of population wellbeing patterns? And, in what ways does analysing wellbeing increase understanding of the experiences of people with multiple conditions?
- Chapter 8, the final chapter, concludes the thesis with a discussion of the overall strengths and weaknesses of the approach followed, including what value it added to the work presented. It then offers some thoughts about where this work could be taken next, with recommendations for potential new analyses as well as further ideas about ways in which the experiences of people with multiple conditions could be more comprehensively reflected in population health surveillance sources such as the Scottish Health Survey.

Chapter 2 Literature Review

Introduction

Aims of this review

This literature review is deliberately broad and is designed to be representative of key themes in the field. In common with the main aims of the thesis, it has prioritised articles concerned with methodological/definitional matters, general population data (rather than those solely drawn from in-patient data), and with wellbeing (the outcome selected to elucidate the experiences of people with multiple conditions in this thesis). Despite being a relatively new field of research, it was still necessary to manage the breadth of this review's scope. Therefore, the sections covering substantive outcomes largely focus on areas that can be described as nearing, or having reached, a consensus within the field. It starts by introducing the concept of multiple conditions, both as a status that people have and as a topic of interest in health research and clinical practice. Its historical emergence is then described, including a chronology of selected key articles, before moving on to the more methodological and substantive aspects of the literature.

Methods

A number of search strategies were used to identify the literature presented here. However, an important source of information was the library of articles maintained by *The International Research Community on Multimorbidity* (IRCM) (International Research Community on Multimorbidity 2015). The IRCM use the terms "multimorbidity", "multi-morbidity" and "multiple chronic conditions" to conduct their searches and while acknowledging that this has the potential to miss articles, Fortin (2013) states that *"we are sure that most publications on the subject are included in the list"*. However, to avoid this review being wholly reliant on one source, additional steps were taken, such as:

- A MedLine search for systematic reviews focusing on multimorbidity or comorbidity published from 2000 onwards (details in Appendix A);
- Following up references in published papers;

- Conducting citation searches of key papers;
- Conducting searches within key journals;
- Consulting publication lists for key data sources, such as the Health Survey for England and English Longitudinal Study of Ageing, to identify "grey" literature.

Although this is not a systematic review, a short quality assessment checklist was used to help appraise the systematic reviews identified (see Appendix A). In addition, to broaden this work beyond purely empirical epidemiological work, and to embed it within a more theoretically-focused approach, a parallel review of work in the sociology of illness literature was also conducted, which encompassed aspects such as disease conceptualisation, classification, illness experiences, diagnosis, medicalisation and overdiagnosis (interest in the last of these aspects spans both sociological and epidemiological research). The overarching approach to integrating this wider sociological literature with the empirical analysis conducted in this thesis is described in Chapter 3, while the insights gained from these areas are presented in Chapter 4.

What is multimorbidity?

As noted in the introduction, the majority of studies in this field use the term *multimorbidity*, whereas I have stated my preference for the term *multiple conditions*. However, as much of the work being considered in this review used the term multimorbidity, the discussion follows this usage where appropriate, but with a preference for using the term multiple conditions as far as is possible.

While the meaning and measurement of multimorbidity is far from straightforward, something approaching a consensus appears to exist around the following two points, first described in detail by Akker et al. (1996):

- comorbidity is used to describe a person with multiple concurrent health conditions, in addition to an index condition of interest;
- multimorbidity is used for situations in which a person has more than one concurrent chronic health condition, without reference to a preeminent or index condition.

However, the absence of a *firm* consensus on this was illustrated in a review by Almirall and Fortin (2013). Similarly, the *European General Practice Research Network* (EGPRN) has been attempting to develop a single multimorbidity definition (Le Reste, Nabbe, Manceau, et al. 2013), as has the IRCM (International Research Community on Multimorbidity 2013).

The nature of this on-going debate appears to be more oriented towards ontological than epistemological concerns, with the focus largely on which multiple conditions should be grouped, and how. More epistemologically-focused questions about whether such measurement is possible are certainly evident (see, for example, Diederichs et al. 2011) but are relatively less common, and are themselves informed by ontological concerns about the nature of multimorbidity.

Tracing the history of these concepts, Valderas et al (2011) describe multimorbidity as: "*a modern alternative to 'comorbidity' … [a] more 'democratic' approach*" (p1). In a similar vein, Boyd & Fortin (2010) describe multimorbidity as a person-centred concept, while Valderas et al. (2009) suggest it is most usefully applied in primary care settings where a generalist focus predominates, with comorbidity more relevant when a specialist approach is needed.

What is meant by a chronic health condition is arguably one of the more complex elements of these definitions, and a considerable amount of space is devoted to considering this in greater detail in Chapter 4. However, it is worth highlighting that concurrency, and the threshold used to determine multiplicity, are both similarly problematic. Furthermore, while some conceptual clarity *generally* surrounds the distinction between multimorbidity and comorbidity, in practice they are often used interchangeably. Studies of comorbidity are considerably more prevalent in the literature (Valderas et al. 2011), while other descriptions, such as multiple chronic conditions, are used in some contexts either in preference to, or as well as, multimorbidity (for example Boyd & Fortin 2010; Walker 2012; Almirall & Fortin 2013; Wallace & Salive 2013). The challenge of conceptualising multiple conditions lies at the heart of this thesis, and a significant proportion of the literature in this field

reflects this problem. However, before these issues are detailed more fully, it is useful to describe when - and why - the concept emerged in the first place.

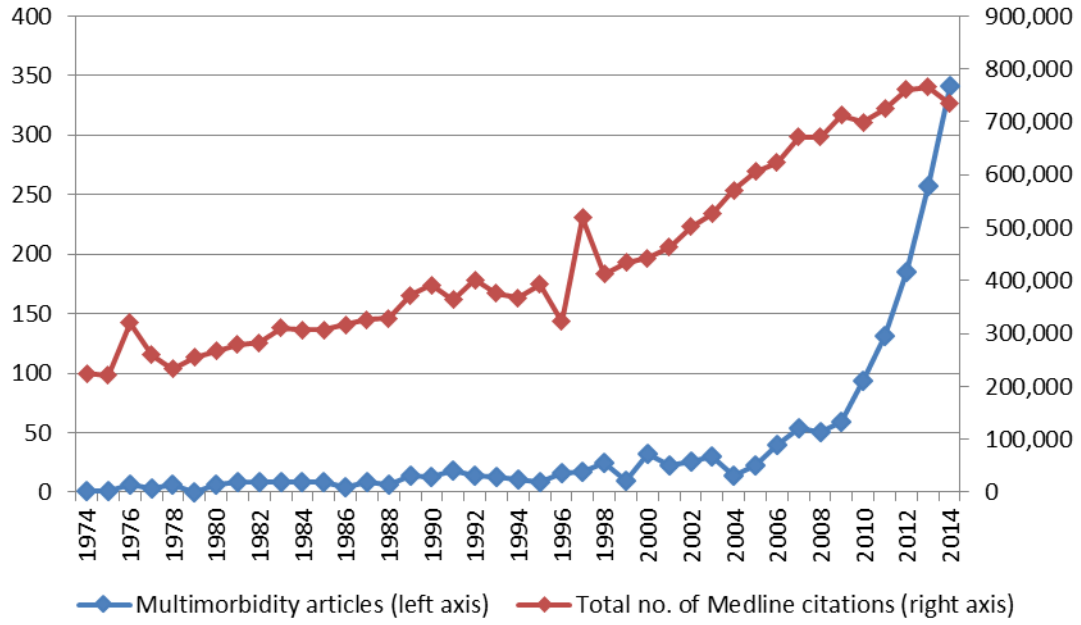
Historical emergence of multimorbidity

Overview of the literature

Le Reste et al. (2013) trace the origins of the term multimorbidity in the research literature to a German article published in 1976,[2] and state that just 72 articles between that point and 1990 contained the term (the vast majority of which were also in German). A search of the MedLine database using the term "multimorbid$ OR multi-morbid$" (limited to humans) yields 1,601 results for the period January 1974 to December 2014. The number of articles published each year (illustrated in Figure 2.1) grew exponentially from the late-2000s onwards. To calibrate this growth against the overall increase in articles in recent times, the graph also shows the total number of citations within MedLine for the same period. It's clear that the recent rate of growth in the number of multimorbidity articles is more than just a reflection of a general growth in publishing.

[2] MedLine contains two articles using the term multimorbidity before this, but the 1976 article was the first to include it as a keyword.

Figure 2.1 Number of articles identified in MedLine search using search term "multimorbid$ OR multi-morbid$",[3] and total number of citations in MedLine,[4] by year, 1974-2014



To help put this in context, Fortin et al. (2005) compared the number of articles identified in MedLine in the 1990-2002 period using the keyword multimorbidity or MeSH term comorbidity, with those related to a selection of single conditions. They found 38 articles on diabetes for every multi/comorbidity article, 74 on asthma and 94 on hypertension. While the recent growth in multimorbidity articles is likely to have reduced the gap between these figures, a MedLine search using the family of diabetes MeSH terms (and excluding multimorbidity articles) yields over 72,000 results for the 2005-2012 period alone, suggesting that the number of articles focused on single diseases still outstrips those for multimorbidity by some margin. While it is hard to identify a single article that fuelled the notable growth in multimorbidity articles from around 2007 onwards, this work by Fortin et al. (2005) was possibly a contributory factor. The volume of work now being produced certainly seems to support Tinetti & Basu's (2014) suggestion that this field is "*no longer in its infancy*" (p.S5), though their qualifying point that "*much remains to be learned and uncovered*" (p.S5) underlines the

[3] Search first conducted on 21 October 2013 and updated 21 November 2015.
[4] Source: http://www.nlm.nih.gov/bsd/index_stats_comp.html (accessed 21 November 2015).

extent to which an increased level of research output does not necessarily result in an increased depth of understanding of a topic.

Bibliometric analyses such as these can be a useful mechanism for tracing the development of concepts. However, caution needs to be exercised when interpreting such results. The data in Figure 2.1 relates to the occurrence of keywords, so the explosion from the mid-2000s onwards could be as much to do with changes in the way that articles are coded in MedLine, rather than changes in their underlying content. This does not necessarily invalidate this approach, as changing practices around the use of particular keywords are reflective of an important research paradigm shift, but it is nevertheless important to temper claims about the growth of a field by recognising the limits of what simple keyword counts can reveal.

Related to the previous point, it is also important to highlight that multimorbidity's relatively recent emergence as a term does not, of course, mean that the fact people can have more than one concurrent condition is also a fairly novel discovery. For example, while death certificates are designed to capture a single cause of death, they have long had space to list additional contributory causes (Bowker & Star 1999). In addition, the burden of multiple conditions has long been a feature of the gerontology literature, as exemplified by a study reported in The Lancet in 1962 which examined 200 patients admitted to the Aberdeen Geriatric Unit in 1957 and found them to have had 1168 diseases between them, an average of six each (Wilson et al. 1962). If replicated now, such research would undoubtedly use the term multimorbidity. Similarly, the psychiatric epidemiology literature has a long-standing interest in the co-occurrence of conditions (see, for example, the references cited in Kraemer 1995).

Chronology of key articles

Despite the recent and rapid growth in research in this area, it is possible to identify a much smaller sub-sample of around 20 key references that have either helped to define the field, or are representative of major developments within it, based on the frequency of their citations or their presentation of work that helped to shift the direction of research in this field, for example by proposing approaches that have subsequently been more widely adopted. This list is neither definitive nor exhaustive,

rather it is intended to be illustrative of work that helps contextualise the historical development of research in this field. With this in mind, the following discussion highlights how these articles reflect key themes in the literature and other important developments in the field. The more thematic discussion that follows afterwards will consider their contents in more detail.

Reflecting the historical development of the concept, the earliest articles that feature prominently in this field discuss the definition and measurement of comorbidity, as opposed to multimorbidity. Feinstein (1970) was the first to outline a clear definition of comorbidity and describe the negative consequences of failing to account for multiple conditions in both research and clinical practice. Kaplan and Feinsten (Kaplan & Feinstein 1974) proposed the first multimorbidity index, for a study of mortality in diabetes patients, which distinguished between types of comorbidity (vascular and non-vascular), as well as their severity. With the exception of Guralnik et al.'s (1989) study of comorbidity and disability in the older population in the USA, very little else was published in the 1970s and 1980s that arguably qualifies as seminal in this field. This changed in the 1990s, when some of the statistical challenges of comorbidity analysis were developed further by Kraemer (1995), and Akker et al. (1996), who were the first to draw a clear distinction between comorbidity and multimorbidity. A little later, Akker et al. (2001) discussed additional statistical and methodological challenges posed by multiple conditions research. This period was not solely devoted to methodological work; Akker et al.'s (1998) study of multimorbidity in the Dutch general population is a good example of an early and widely cited prevalence study (147 citations in PubMed as of December 2015[5]). The early 2000s saw more work on the methodological aspects of research in this field, with de Groot et al. (2003) stating that consensus about the definition of comorbidity and multimorbidity had not yet been reached.

Some key articles about the impact of multimorbidity on health outcomes and its implications for primary care also date from this period. These include Fortin et al.'s (2004) systematic review of multimorbidity and quality of life; Tinetti et al. (2004) and

[5] http://www.ncbi.nlm.nih.gov/pubmed/9619963 [Accessed 27 December 2015].

Boyd et al.'s (Boyd et al. 2005) work highlighting the problems of applying single-disease clinical guidelines to people with multimorbidity (an approach that continues to be applied in other work, e.g. Hughes et al. (2013)); and Vogeli et al.'s (2007) wide-ranging study of multimorbidity prevalence and its impact on health outcomes, service use and care delivery. Around the same time, Fortin et al. (2005) highlighted the lack of research on multimorbidity relative to single diseases (discussed previously), and the IRCM,[6] coordinated by the University of Sherbrooke in Canada, was established as a virtual network of researchers in this field to try and address this and other concerns (Fortin et al. 2007).

Methodological concerns were, however, ever present in this era – Valderas et al. (2009) highlighted ongoing problems with the lack of conceptual clarity surrounding comorbidity and multimorbidity research, and outlined some clear guiding principles to help standardise research practice in the field. Boyd and Fortin (2010) continued to promote the need for health systems and research to better meet the needs of people with multimorbidity, with a particular emphasis on the importance of patient-centred care, but also devoted time to the critically important issue of defining multimorbidity.

2011 saw the founding of the *Journal of Comorbidity*, envisaged to be a platform for research about multiple conditions and their management (Valderas et al. 2011); its choice of title possibly reflecting continuing ambiguity around nomenclature in this field. The first edition included articles spanning most of the main themes highlighted in the above discussion: methodological challenges, health care implications, prevalence, and future research needs related to multiple conditions.

The current decade has also started to see an increasing number of systematic reviews, concerning both the impact and measurement of multimorbidity. These include Marengoni et al.'s (2011) wide ranging review of multimorbidity in the ageing population, with its strikingly wide prevalence estimate range of 55-98% now highly cited. While a consensus that multimorbidity refers to multiple conditions within the same individual appears to be emerging, Diederichs et al.'s (2011) review of

[6] http://www.usherbrooke.ca/crmcspl/en/international-research-community-on-multimorbidity/

multimorbidity indices provided an invaluable insight into the huge variability in how this has been applied in the literature: the number of conditions used to define multimorbidity in the studies they reviewed ranged from four to 102. Fortin et al.'s (2012) systematic review of prevalence studies drew similar conclusions surrounding the problem of inconsistent definitions. They made recommendations about the ideal number of conditions to include (at least 12), and suggested reporting multimorbidity prevalence based on two thresholds (at least two conditions, and at least three), but did not make firm recommendations about which underlying conditions to include, though stated that high prevalence, impact and burden would be useful selection criteria. Subsequent to this, Huntley et al. (2012a) conducted a similar (but far wider-ranging) review of multimorbidity measures for use in non-clinical settings. By arguing that "*[i]t is important that measures are based on an underlying conceptualisation of why and how multimorbidity is expected to have an impact on other variables*" (Huntley et al. 2012a, p.139) their work arguably demonstrated an important attempt to move the debate about multimorbidity definitions away from purely mechanistic issues, towards more theoretically-informed approaches.

Moving away from methodological debates, two key articles of relevance to the UK setting provided the first nationally-representative estimates of multimorbidity prevalence using primary care data in England (Salisbury et al. 2011) and Scotland (Barnett et al. 2012). The latter article subsequently won the 2013 Royal College of General Practitioners prize for best research paper of the year (BBC 2013), and the data source has since been used to produce additional analyses (McLean et al. 2014; Smith et al. 2014; Cooper et al. 2015).

The final papers to highlight here are a Cochrane Review of interventions for managing patients with multiple conditions outside hospital settings (Smith et al. 2012), and an article outlining recommendations for the design and evaluation of such interventions (Smith et al. 2013). These arguably illustrate the distance travelled by research in this field over the past few decades, from a preoccupation with methodology towards an increasing emphasis on the consequences for individuals with multiple conditions. However, Smith et al. (2012) also illustrate ongoing deficiencies

in this field: just 10 studies were identified for inclusion in the review, with mixed results.

The above discussion has presented an historical overview of the emergence of multiple conditions as a concept in the research literature. It has not, however, addressed the question of *why* this came about. Its emergence can be linked to a number of factors, including wider societal trends, such as population ageing, as well as to changes in the nature of healthcare delivery and the conceptualisation of disease, and also to transformations in the roles performed by, and the relationship between, clinicians and patients. Some of these are considered in more detail below, others are explored further in Chapters 4.

The role of the epidemiologic transition and demographic change

Some of the most significant drivers of the emergence of multiple conditions as a status of interest (and as a state of being) can be traced to the major demographic changes seen in most parts of the world across the twentieth century. These have dramatically changed the nature of the disease burden and the age profile of populations, a process described as the 'epidemiologic transition' (Omran 1971). The key features of this transition can be summarised as: the decline in infectious disease mortality coupled with a corresponding increase in chronic non-communicable disease (NCD) morbidity and mortality, increasing life expectancy, declining fertility and, as a consequence, an ageing population (Taylor & Bury 2007). Omran (1971) was very clear that the main drivers of this transition were linked to the processes of social and economic change prevailing as societies modernised, with the contribution of medicine "*largely inadvertent until the twentieth century*" (p.520).

The scale of these changes is evident both globally and locally. To illustrate, as recently as 1970, the proportion of the world's population aged under five was around three times higher than the proportion aged 65 and over. A decline in the former and an increase in the latter means estimates now suggest that, by 2020, the older age group will be larger than the younger (National Institutes of Health 2011). In 2012, the proportion of Scotland's population aged under 16 exactly matched the proportion aged 65 and over (17%). However, these figures mask notable on-going changes in the

age structure and the fact that, between 2010 and 2035, the proportion of the population aged 65-74 is projected to increase by 46%, and by 82% for the 75 and over group, whereas the corresponding figures for the rest of the population range from just 3% for the under 16s to -3% for the 16-29 group (Registrar General for Scotland 2013).

Increasing age is a key risk factor for chronic NCD onset. Multimorbidity is usually defined as the presence of multiple *chronic* conditions, so it is therefore unsurprising that many articles on this topic make reference to the trends outlined in the epidemiologic transition model (Caughey & Roughead 2011; Marengoni et al. 2011; Fortin et al. 2012; Diederichs et al. 2011; Salive 2013). However, studies are increasingly highlighting the prevalence of multiple conditions in younger age groups and challenging its status as an exclusively geriatric phenomenon (Taylor et al. 2010; Barnett et al. 2012). In addition, low and middle income countries are also seeing a different pattern emerge as a result of what Oni et al. (2014, p.2) describe as "*colliding epidemics of NCD and ICD [infectious chronic disease]*". The multiple condition burden in these countries has a much younger age profile than that seen for NCDs in high income countries, due to the younger age of people with TB and HIV.

The epidemiologic transition model is not universally accepted, though. As Hyde and Rosie (2012) argue, its critics mostly focus on the model's applicability to settings beyond the developed world, or propose extensions to it, without necessarily questioning its original premise. Armstrong (2013), however, does just this, arguing that changes in mortality and morbidity patterns over the course of the twentieth century were largely driven by the pathologising of ageing wherein conditions and deaths previously attributed to old age are now given more clinical definitions, such as heart disease. While this thought-provoking account makes some valid points about the socio-contextual nature of disease and illness classification (which are developed further in Chapter 4), the fact remains that outwith Africa, life expectancy is rising, acute infectious diseases no longer cause deaths in the numbers they once did, and the WHO estimates that almost two-thirds of all deaths globally in 2008 were caused by NCDs (WHO 2011). Such patterns cannot reasonably be wholly attributed to changes

in the definitions used in death certificates. While critiques like Armstrong's remain in the minority, more extensive debate surrounds the consequences and implications of these demographic changes, particularly for older age groups (Christensen et al. 2009; Rechel et al. 2013), and significant resources are now devoted to the cross-national study of ageing (National Institutes of Health 2011).

Rechel et al. (2013) present evidence to help assess three potential morbidity patterns as a consequence of population ageing: compression (decreasing years spent in ill-health as a proportion of total lifespan), expansion (increase in years spent in ill-health outstripping increases in total lifespan) and equilibrium (years of ill-health as a proportion of total lifespan staying broadly stable). The compression of morbidity model is of particular significance to public health because its successful realisation, as originally outlined by Fries (1980), is premised on four preventative interventions: primordial (risk factor prevention), primary (risk factor reduction), secondary (disease progression prevention), and tertiary (disease amelioration rather than elimination) (Fries et al. 2011, p.2). Rechel et al. (2013) suggest that the evidence in support of these models is mixed, while Fries et al. (2011) describe various sources of evidence as providing proof of concept that compression of morbidity is possible in certain circumstances, if not necessarily inevitable (for example, they demonstrated that older physically active people enjoyed more years of disability-free life than inactive controls). In contrast, analyses presented by Crimmins (2010) conclude: "*…compression of morbidity may be as illusory as immortality.*" (p.83).

Huge variability in patterns and experiences of ageing exist, both within and between countries, related to markers of socio-economic status such as income, education and social class, as well as in access to health care, which arguably make attempts to identify distinct models of ageing rather problematic. For example, the fact that Rechel et al. (2013) describe the evidence in support of the various models as mixed could in part be due to there being different experiences operating simultaneously within the same population; the search for evidence to conclusively support a single model is therefore arguably misguided (Krieger (2011) critiques the epidemiologic transition model on similar grounds).

More recently, Chatterji et al. (2014) also concluded that variations exist between different countries in the extent to which they are experiencing compressions or expansions in morbidity but, along with Beard & Bloom (2014), argued that better and more consistently harmonised evidence is needed, including a move towards more emphasis on functional capacity as opposed to solely focusing on disease burden *per se*. Significantly, Beard & Bloom (2014) suggest that the rise of multiple conditions at older ages makes functional assessment a more important aspect to consider (clinically, in research, and in wider public health policy), arguing that *"[f]unctional assessments of these syndromes [frailty, impaired cognition, continence, gait and balance] are better predictors of survival than the presence or number of specific diseases*" (p.659).

An important issue for this field of research is therefore whether to conceptualise multimorbidity as an inevitable consequence of the natural ageing process that needs to be actively monitored and managed. Or, instead, whether it is also (or alternatively) a consequence of the wider structural factors underlying both the increase in, and unequal distribution of, NCDs (Beaglehole et al. 2011), which potentially offers opportunities for preventative strategies, though only if the correct policies are implemented, which they rarely are (Frank et al. 2015; Douglas 2015). There isn't space here for an exhaustive account of this issue, but the principal drivers of health inequalities, including those observed in NCD prevalence, are now widely accepted, within social epidemiology and public health circles at least, to originate in socio-structural inequalities (e.g. Link & Phelan's theory of fundamental causes (Phelan et al. 2010) and Wilkinson & Pickett's work on income inequality (Wilkinson & Pickett 2009; Pickett & Wilkinson 2015). Following on from this observation is the fact that the rising levels of inequality experienced in the UK in the past four decades (as in most of the world) have themselves been caused by the particular kinds of economic and political policies that have become predominant (Schrecker & Bambra 2015; Collins et al. 2015). These policies are typically labelled neoliberal, though neoliberalism is more appropriately conceived of as having multiple, context-dependent, forms rather than as a single, specific entity (Collins et al. 2015). If the account suggested by Collins et al. (2015) that the connection between neoliberalism

and health inequality is "*clear, well known and causal*" (p.131) is accepted, then another potential explanation for the increasing prevalence and prominence of multiple chronic NCDs in recent decades is that they are an inevitable consequence of neoliberalism, as opposed to being an inevitability of ageing populations.

The growth of concerns about health care costs and sustainability

Rising attention to the fact that populations are ageing has led to concerns about the financial costs associated with growing numbers of chronically ill people, and the demands they place on health and social care systems. Thus the rise of multimorbidity as a concept can also be traced to debates such as these. However, tensions are evident in the wider ageing literature surrounding the issue of rising costs, with some arguing that other factors, such as end-of-life treatment (and hence, proximity to death), and new health technologies drive costs, rather than age *per se* (Lloyd-Sherlock 2000; Seshamani & Gray 2004; Felder et al. 2010). It is worth noting that recent accounts suggest that ageing and health technology demands interact, and caution against treating them as separate, unrelated cost drivers (Breyer et al. 2011; Meijer et al. 2013). Similarly, concerns have been raised about the negative characterisation of ageing evident in much of the literature and policy debates (Lloyd-Sherlock et al. 2012), and the potential fallacy of characterising all people above retirement-age as "dependent", with those below it bearing their costs (Spijker & MacInnes, 2013). Irrespective of the nature of the relationship between ageing and healthcare costs, it is clear that much multimorbidity research has been motivated by concerns about the healthcare 'burden' associated with treating people with multiple conditions, with healthcare utilisation and costs a prominent feature of the literature (for example: Vogeli et al. 2007; Glynn et al. 2011; Huntley et al. 2012b; Steiner & Friedman 2013). All these studies have found multimorbidity to be associated with increased costs, and figures for the US suggest that two-thirds of healthcare expenditure is accounted for by people with multiple chronic conditions (Goodman et al. 2012) – a figure that is now routinely cited in US-based studies of this topic (for example, LeRoy et al. 2014). Few of these studies directly address what proportion of these costs can be attributed to inefficient healthcare delivery, unhelpful polypharmacy, overtreatment, or adverse consequences of conflicting treatments, all of which are known features of healthcare in the context

of multiple conditions, especially – though not exclusively – in the USA (Hitchcock Noël et al. 2007; Boyd & Fortin 2010; Nobili et al. 2011; Hughes et al. 2013). Furthermore, no clear indication is ever given as to whether the cost figures cited represent an appropriate level of resource utilization, or whether these kind of statements are intended to highlight "disproportionate" resource consumption. However, as this group is clearly comprised of people with the greatest health burdens, it is an almost banal point – shouldn't the majority of healthcare costs be directed towards people with the worst health? Indeed, it might be more remarkable if this *wasn't* the case, given how little most countries health systems spend on preventative and wider public health measures. This critique is not intended to deny the increasing complexity of healthcare, and therefore costs, associated with treating people with multiple conditions, but it is intended to highlight that the coupling of these two phenomena can be problematic – and potentially stigmatizing - if it is not accompanied by more nuanced accounts of the underlying dynamics.

Multiple conditions as a challenge to the single disease model

In addition to the macro-level trends outlined above, there have also been important developments in the delivery of healthcare that have contributed towards the recognition of multimorbidity. One such development is the rising use of clinical guidelines.

Weisz et al. (2007) described the presence of clinical guidelines in modern medicine as "*ubiquitous*" (p.691). In the UK, for example, the National Institute for Health and Care Excellence (NICE) lists 165 clinical guidelines on its website (not including its various public health recommendations) (NICE 2015a), developed specifically for use in the UK, while the Scottish Intercollegiate Guidelines Network (SIGN) lists around 50 (guidelines labelled "use with caution" or "withdrawn" have been excluded from this figure) (SIGN 2015). These figures do not include the very large number of additional guidelines issued by bodies such as the UK's Royal Colleges, and organisations representing clinical specialities who, in the USA in particular, occupy a highly influential role in the healthcare system. The use of such guidelines is standard practice across the developed world, though their coordination is poor and

recommendations for the same conditions can vary widely, to the extent that bodies such as the Guidelines International Network have been established to try and better coordinate their development and use (GIN 2013).

Various reasons have been cited for the growing use of guidelines, including concern about variations in practice leading to unnecessary costs, wasteful or inefficient care, or inequitable outcomes; professionals' desire for self-regulation; the modern-era's proliferation of medical research and the need to translate findings into practice recommendations; the need to standardise an increasingly complex and fragmented healthcare system; and a reining-in of clinical autonomy (Woolf et al. 1999; Harrison & Ahmad 2000; Weisz et al. 2007). The critical feature of clinical guidelines is that they almost exclusively adopt a single disease approach and focus on the diagnosis and management of one condition with scant reference to comorbidities. The rising use of such guidelines has, therefore, arguably made the challenges of treating people with multiple conditions much more apparent than might otherwise have been the case. This recognition has not only increased the prominence of multimorbidity, but it has also brought into question the practicality and desirability of the single-disease model and guideline-driven care (Tinetti et al. 2004; Boyd et al. 2005; Boyd & Fortin 2010; Lugtenberg et al. 2011; Reuben & Tinetti 2012; Guthrie, Payne, et al. 2012; Hughes et al. 2013; Wyatt et al. 2014).

As noted above, one consequence of treating people with multimorbidity as if they were no more than the sum of each single condition can be polypharmacy – the prescribing of multiple medications – which brings with it the potential for harmful drug interactions, poor treatment adherence (linked to the complexity and burden of taking multiple drugs), high costs and the risk of developing further comorbidities. Both Boyd et al. (2005) and Hughes et al. (2013) outline the treatment regimes that a selection of hypothetical patients with multiple conditions would be subject to, and highlight the large number of drugs they could potentially be prescribed. This situation is particularly apparent in the older population, where additional problems arise from not just the potential for negative interactions between drugs, but also from the fact that the physical effects of ageing have consequences for prescribing that need to be

considered (Nobili et al. 2011). Polypharmacy is not in itself problematic, as Hughes et al. (2013) note, nor does the application of guidelines always result in the overtreatment of people with multiple conditions (Roland & Paddison 2013) – if the recommended drugs and other interventions are vital to maintaining a person's health and quality of life, have no negative interactions and do not impose a treatment burden that outweighs their benefits. The critical point is that healthcare systems are widely acknowledged to be highly specialised, and therefore often fragmented, so not only do guidelines rarely cross-reference treatment recommendations, but the system delivering them is similarly ill-coordinated and not well-placed to effectively manage people with multimorbidities. Situations such as unhelpful polypharmacy and overtreatment therefore arise as a consequence of how healthcare is delivered, and not as a result of multimorbidity *per se*. This point applies in many countries (Nobili et al. 2011), and has been identified as a specific cause of problems for people with multiple conditions for over a decade (Wright et al. 2003; Bayliss 2012).

A further example of the failure of the single-disease model arises from the exclusion of people with multiple conditions from most of the clinical trials that are conducted in medical and public health research – many of which are used in the development of the drugs and clinical guidelines used in the treatment of people with multiple conditions (Fortin et al. 2006; Fortin et al. 2007). The extent that this occurs was illustrated in a study by Boyd et al. (2012) which reviewed the trials reported within 11 Cochrane Reviews covering four chronic conditions. The study found that people with comorbidities were often excluded, and where they were not, the existence of effect modification for people with comorbidities was not often reported. Interestingly, the problem of clinical trials lacking external validity to multimorbid populations was highlighted over forty years ago by Feinstein (1970).

Concerns about the sustainability of the single-disease model are also evident beyond the epidemiological and largely quantitative literature considered so far. As will be discussed further in Chapter 4, the many dimensions of people's lived experiences of chronic illness has long been a central theme in the sociology of health and illness field (Gerhardt 1989; Bury 1991; Kelly & Field 2004; Taylor & Bury 2007; Bury

2010). However, most (if not all) of this work was grounded in research focusing on single conditions, and Kelly & Field (2004) also suggest that the field has been dominated by studies of "*exotic*" or "*intractable*" (p.257) conditions, rather than those more commonly seen by GPs, though attempts have been made to redress this single disease focus (Townsend et al. 2003; Townsend et al. 2006; Sells et al. 2009; Morris et al. 2011; Hurd Clarke & Bennett 2013; Ong et al. 2014; O'Brien et al. 2014). Similarly, representations of illness is a prominent field within health psychology research, and work has started to adapt and update this concept in the context of multiple conditions (Bower et al. 2012). However, compared with the growth of epidemiological research on multimorbidity, its presence in the sociology of health and illness and health psychology literature appears to be comparatively less well-established.

Multiple conditions as reflected in changing roles

The decline of the single-disease model, and corresponding growing recognition of multiple conditions, can also be linked to wider changes within society and the practice of medicine, in which there has been a decline in clinical autonomy and deference to professionals, and an alteration to the roles occupied by clinicians and patients (Coulter 1999; Harrison & Ahmad 2000; Scambler 2002; Nettleton 2004; Stevenson & Scambler 2005). Many of the causes that have been attributed to this phenomenon are not directly relevant to this discussion, but those that are include the increasing prevalence of chronic illness, whose long duration affords people extended periods over which to gain knowledge about their conditions and their management; rising education levels; the widening of access to health information (accelerated by the advent of the internet) and its prominence in the media; and the role of social media as a forum for people to share their illness experiences (Stevenson & Scambler 2005; Mazanderani et al. 2013).

Amongst all these changes, a shift towards a more person-centred approach to health care can certainly be identified, including the rise of the so-called "expert patient", though the motivations behind it and the genuine extent to which it has been realised have rightly been questioned (Bury 2010). The emergence of a concept such as

multimorbidity can, however, be seen as integral to trends such as these. Acknowledging – and taking seriously – the fact that people can and often do have multiple conditions, arguably reflects an approach that de-emphasises single diseases (around which much of the medical establishment is built), and better reflects the reality of people's experiences of living with chronic conditions. Clearly it is not the sole reason why multimorbidity has become a matter of concern, but it is hard to imagine how it would have done so without there also having been changes to the way in which clinicians view and value their patients. However, as will be seen, the extent to which definitions of multimorbidity take into account the experiences and preferences of people with multiple conditions is rather limited.

Having outlined some of the key factors that have contributed to the emergence of multimorbidity as a concept, the remainder of this review highlights the key points of consensus evident in the literature to date, and signals some of the more recent developments that are starting to feature more prominently. However, before doing this, a brief outline of some of the key measurement challenges facing this field is presented.

Multiple conditions, multiple measures

As the above discussion of the historical emergence of multimorbidity hopefully demonstrated, its measurement has long been, and continues to be, fraught with difficulties. Goodman et al. (2013) contrast the clarity and precision found in infectious disease classification with the many layers of heterogeneity associated with chronic disease and multiple conditions coding.

As touched on previously, Almirall and Fortin (2013) conducted a bibliometric analysis of the following terms, all found in the literature in this field, covering the period from 1970 to 2012: comorbidity, multimorbidity, polymorbidity, polypathology, pluripathology, multipathology and multicondition. Additionally, they conducted a review of multimorbidity definitions. The key finding was that comorbidity was the most commonly used of these terms by some margin, followed by multimorbidity. The majority of articles using the term comorbidity adhered to Feinstein's (1970) original definition and included an index condition, though 17%

did not. Most articles using the term multimorbidity did not define it, and that where it was defined, 13 different definitions could be identified (the issue of which conditions were included in the definition was not addressed). The authors stated that they hoped this work would help to develop a consensus on these definitional matters, and organised an online survey between December 2013 and January 2014, via the IRCM (International Research Community on Multimorbidity 2013). This gathered views on whether the definition of multimorbidity should stipulate that the conditions included are chronic/long-term (the key distinction between the two multimorbidity definitions that span 91% of the articles in their review). The majority (69%) of respondents favoured this definition:

> Multiple co-occurring chronic or long-term diseases or conditions, none considered as index disease. (International Research Community on Multimorbidity 2014).

A further 17% wanted no reference to the chronicity / duration of conditions within the definition, 7% didn't have a preference between these options, and 7% opted for another (unspecified) definition. However, clarity over the temporal nature of the conditions included is not, arguably, the only problem confronting the definition and measurement of multimorbidity. Additional challenging factors that need to be considered include how individual conditions have been defined and identified, how data have been collected, which populations the data apply to, how much granularity is possible, whether severity should be factored in, and what counts as multiplicity. It seems implicit in the definition above that multiple means more than one, however, the fact that this does not provide particularly good discrimination in older populations (most of whom have more than one condition) has resulted in some studies using a threshold of three or more (e.g. Bussche et al. 2011; Harrison et al. 2014). Fortin et al. (2012) recommend reporting both thresholds (two or more and three or more), though this has not been widely followed, and Harrison et al. (2014) suggest that significant underestimation could arise from using a threshold of three or more unless datasets included all potential conditions (though they describe the lower threshold as insufficiently specific to be useful).

Arguably the two most fundamental issues appear to be: what conditions should be counted, and how this should be done. However, it appears that more of the literature has been devoted to the construction of weighting methods (Groot et al. 2003; Huntley et al. 2012a; Sharabiani et al. 2012; Diederichs et al. 2012), with the issue of what underlying conditions should comprise measures of multimorbidity rarely treated as important (Diederichs et al. 2011). To illustrate, the extensive review by Huntley et al. (2012a) considered 194 articles spanning 184 studies. They grouped them according to the counting method employed, with supplementary material providing an alternative typology grouping the studies according to their main research findings. Both these methods of presenting the findings provided valuable information in an accessible format, but the actual conditions included in the studies were not detailed, nor did they merit much discussion, which rather leaves the impression that this is unimportant. This approach was also true of the reviews by Fortin et al. (2012), Marengoni et al. (2011), and Salive (2013). Although Violan et al. (2014) did not document the conditions covered by their systematic review of prevalence, it included an analysis of condition clusters (an increasingly common line of inquiry in this field, as noted below), hence the question of what conditions had actually been included was a little more prominent in their work. However, the extent to which a measure has captured a partial or more comprehensive picture of people's morbidity burden will surely affect the generalisability of any findings to the population, and it is striking how few studies in this field include mental health conditions (though, as subsequent chapters will demonstrate, there are numerous methodological and logistical reasons why this is not surprising). The impact of this inconsistency is most telling when reviews of prevalence are conducted, as they will invariably yield results with such wide variations that arguably the most appropriate conclusion that can be drawn is simply that different definitions generate different prevalence estimates – such as the 55-98% range presented by Marengoni et al. (2011) for the older population, and the 12.9% to 95.1% cited by Violan et al. (2014).

Diederichs et al.'s (2011) review is the only detailed examination that exists of the heterogeneity of conditions within multimorbidity indices, and its findings shed light on why underlying conditions tend to be absent from systematic reviews: 25 studies

were excluded from the review because the conditions used to define multimorbidity had not been specified, and of the 39 studies that were included, only 16 contained an explicit rationale for the chosen conditions. Pragmatism and expediency therefore appear to be the driving force behind the selection of conditions in much of the literature, with data availability the most common constraint, and opacity about this issue seems to be commonplace (Almirall & Fortin 2013).

The direct experiences of people who actually have multiple conditions has received scant attention in the literature. For example, the process of establishing a multiple chronic conditions definition for use in US health research, as described by Goodman et al. (2013), used expert opinion from clinicians, epidemiologists and public health specialists to come up with 20 conditions based on their chronicity, prevalence and whether they were amenable to interventions. They do not mention involving patient groups, or whether patient views were considered in the process. Similarly, the attempt by the European General Practice Research Network (EGPRN) to devise an "*exhaustive definition of multimorbidity drawn from scientific literature*" (Le Reste, Nabbe, Lygidakis, et al. 2013, p.132) for use across studies in primary care settings to help standardise work in this field was informed by qualitative work with GPs, but not with people with multiple conditions. This work was also criticised for failing to consult with key members of the international multimorbidity research community (Almirall & Fortin 2013).

While Diederichs et al. (2011) recommend 11 high prevalence conditions that should be included in future indices, they also voice doubts about the utility of operationalising a complex concept such as multimorbidity using a simple definition based on two or more chronic conditions. Instead, they highlight the need for other dimensions to also be taken into consideration, such as the extent to which conditions impact on people's quality of life and functioning, as Reuben & Tinetti (2012) also argue. In a similar vein, others suggest going further than this, for example by using complexity measures, or indicators of functional capability, that capture far more about a person's situation than the sum of their conditions (Safford et al. 2007; Valderas et al. 2009; Mercer et al. 2009; Schaink et al. 2012; Grembowski et al. 2014;

Beard & Bloom 2014; Chrischilles et al. 2014; Koroukian et al. 2015). Analyses using techniques to cluster people according to their condition types have also become more common recently - Prados-Torres et al. (2014) identified 14 articles to include in a systematic review, only four of which had been published before 2010. These analyses attempt to identify common patterns of occurrence that could potentially yield insights about causal pathways between conditions, or identify combinations particularly likely to cause significant burdens for people. However, the value of identifying such patterns has, arguably, yet to be fully realised.

The EGPRN's attempt to develop a multimorbidity definition (Le Reste, Nabbe, Manceau, et al. 2013), the criticism it has faced (Almirall & Fortin 2013), and the counter attempt by the IRCM (International Research Community on Multimorbidity 2013) to do the same (described above), further illustrates the possibility that multimorbidity might not be a concept to which a single definition can be applied. Following a systematic review, the EGPRN proposed the following (Le Reste, Nabbe, Manceau, et al. 2013):

> Multimorbidity is defined as any combination of chronic disease with at least one other disease (acute or chronic) or bio-psychosocial factor (associated or not) or somatic risk factor.
>
> Any biopsychosocial factor, any somatic risk factor, the social network, the burden of diseases, the health care consumption, and the patient's coping strategies may function as modifiers (of the effects of multimorbidity).
>
> Multimorbidity may modify the health outcomes and lead to an increased disability or a decreased quality of life or frailty.

This definition has also now been translated into 10 European languages (Le Reste et al. 2015). This bears little resemblance to the commonly used definitions identified in Almirall and Fortin's (2013) review. This is partly understandable, as it was developed to bring clarity to this very muddled field, but it is arguably undermined by its length, by including terms that themselves need further clarification (e.g. bio-psychosocial), and by its breadth, particularly its inclusion of acute disease and other risk factors. This definition has the potential to classify the vast majority of the population over 50

with a chronic condition as having multiple conditions, a situation that probably warrants a discussion far beyond the scope of the task the EGPRN originally set itself.

The challenges raised by these definitional issues recur throughout this thesis. As noted in the introduction (Chapter 1), its title - Beyond a Boundary - was chosen to reflect the fact that many boundaries exist that require consideration in the process of identifying people with multiple conditions. For example, whether multiplicity is defined as more than one condition, or more than two; how to handle health states that straddle the boundaries between conditions and risks, normality and abnormality; and how the boundary between clinical and lay voices is best approached. But it is also intended as a challenge to the idea that the resolution of these boundary issues is merely a technical matter; that there exists a perfect measure of this status that just needs to be identified, and, indeed, that this status has a fixed form that is amenable to measurement in the first place.

These kinds of considerations stray into the territory of some of the more fundamental, philosophical, questions surrounding the nature of health, illness and classification that are considered in more depth in Chapter 4. However, a more prosaic challenge must also be considered - that of actually sourcing the basic information necessary to create measures of multiple conditions. A key aspect of this is considered next.

Multiple conditions, multiple sources

It seems an obvious point, but the prevalence of people with multiple health conditions can only be established by ascertaining information about the single conditions people have. Health data come in many forms – the majority of the studies cited so far were derived from administrative data sources from primary care, or sometimes hospital, settings - but the question of what can be collected directly from people themselves, via population health surveys, is clearly of most relevance to the work presented in this thesis. Self-reported data are often omitted from reviews of conditions on the grounds of data quality (e.g. Violan et al. 2014). In contrast, Huntley et al. (2012a) make the point that self-reported data sources have the advantage of being able to incorporate direct reports from people about any functional

impairments, and are therefore critical for studies of quality of life. Fortin et al. (2012) concluded that self-reported data are best augmented by additional sources, such as medical records, but do make the point that medical records too have limitations that self-reports can help to address (such as missing or out of date information).

The measurement of health spans a vast literature and identifying conditions (diagnosed or otherwise) occupies only a very small part of this (see, for example, Bowling 2001; Bowling 2005). Basing estimates on people's own reports of what conditions they have received diagnoses of requires a number of criteria to be fulfilled: they need to have been told their diagnosis (this cannot be assumed in all cases), they need to have understood what they were told, remember having been told, agree with the diagnosis, and be prepared to volunteer that information to a third party (e.g. a survey interviewer). What is less often noted is that such diagnoses – if they are to truly reflect someone's current state of health – also need to have been accurate in the first place, and they need to still be valid at the time the survey is undertaken. Any one of these criteria can fail and therefore result in the kinds of discrepancies that are commonly reported in the methodological literature on health measurement. For example, diabetes reporting is generally accurate (Kriegsman et al. 1996; Goldman 2003; Okura et al. 2004; Pastorino et al. 2015), hypertension is much less so (Goldman 2003; Tolonen, Koponen, Mindell, Männistö, Giampaoli, et al. 2014), though not uniformly so (Okura et al. 2004). Cardiac events have been found to be both under and over-reported relative to medical records (Yasaitis et al. 2015). Kriegsman et al. (1996) also found the concordance between self-reported and medical record estimates of arthritis to be generally quite poor.

Gooberman-Hill et al.'s (2003) qualitative study of the responses older people gave to a survey question intended to measure long-term conditions among the general population is of particular interest to the work in this thesis. In addition to the potential problems outlined above, this study highlighted the complexity of the judgements being made about what should, or should not, be reported, in part linked to people's experiences of symptoms, their understandings of health and the nature of conditions, and the extent to which they identified with certain health conditions as

illnesses or as inevitabilities of the ageing process. Some of these were related to cultural and generational differences, and Gooberman-Hill et al. (2003, p.2556) raise the following possibility:

> While we would expect that some survey items may not capture the meaning of health and illness, this also implies that they may not capture the prevalence of chronic conditions among older people.

Related to this, Hansen et al. (2014) highlighted differences between GP and patient reports of conditions among people with multiple conditions in Germany. This study didn't use medical records as the comparative source of data, but instead used physician's reports (which other studies have found to be fairly inaccurate (Merkin et al. 2007)). This had the advantage that they could use focus groups to explore reasons for some of the discrepancies between the patient and physician accounts (Hansen et al. 2015). Patients gave greater priority in their illness accounts to conditions with more invasive symptom burdens, whereas physicians gave greater weight to conditions with life-shortening prognoses, which suggests that another important aspect affecting people's propensity to report conditions, especially when they have multiples of them, is the extent of their immediate impact on their daily lives.

This thesis is specifically interested in estimating prevalence of multiple conditions using self-reported data so there is little to be gained from a more exhaustive consideration of its merits relative to other sources. However, the sources of the discrepancies that have been found to exist, the fact they vary by condition type, and the groups among whom they are most common (typically, but not exclusively, older people and those with lower levels of education) are all highly relevant and will recur throughout this thesis.

Moving away from the methodological aspects of this work, the remaining sections of this chapter now describe what appear to be the main points of consensus that have emerged in relation to the impact of multiple conditions. The matter of how multiple conditions as a single status has been defined, and the potential consequences of the measurement heterogeneity outlined above are, therefore, largely absent from the remaining discussion, except where it is pertinent to the conclusions being drawn.

Emerging consensus around multimorbidity

Demographic and socio-economic profile of multimorbidity

Perhaps the most universally reported observation about multimorbidity patterning is that it increases with age. For example, systematic reviews of prevalence studies in both primary care settings and the general population show that the increase in multimorbidity prevalence with age generally follows an S-shaped curve (Fortin et al. 2012). Huntley et al.'s (2012b) large-scale review of multimorbidity definitions shows that age is associated with increasing multimorbidity prevalence, across a number of different multimorbidity measures. Numerous other studies, not included in the Fortin et al. review (mainly due to their timing), support this finding (Taylor et al. 2010; Salisbury et al. 2011; Barnett et al. 2012; Ward & Schiller 2013; Lochner & Cox 2013; Violan et al. 2014). Many of these studies also make a point of drawing attention to the multimorbidity burden in the population aged under 65 years to highlight the fact that, despite increasing with age, multimorbidity should not be treated as a topic of relevance solely to the older population (a point also made by Mercer et al. (2009)). Indeed, while studies of people's experiences of living with multiple conditions have more commonly focused on older populations, recent qualitative work has attempted to redress this balance (e.g. O'Brien et al. 2014; Duguay et al. 2014), with the participants in Duguay et al. (2014) describing their illness experiences as a form of premature ageing.

The majority of studies reviewed by Violan et al. (2014) report a higher prevalence of multimorbidity in women than men, as did the main UK-based studies (Barnett et al. 2012; Salisbury et al. 2011) though this is not universal (Huntley et al. 2012b), and the magnitude of the difference varies depending on the study design, age range analysed, and multimorbidity definition used (see, for example: Ward & Schiller 2013). It is highly likely that gender differences in the underlying conditions included in multimorbidity definitions will contribute to such differences in outcomes between studies.

Analyses using measures of socio-economic status appear to be less common in the literature than those reporting age or sex differences. This is likely to be due to the fact

that many studies are based on administrative data, such as health records, which often have limited access to socio-economic measures. The presence of socio-economic gradients in multimorbidity has, however, been clear from quite early on in the history of its reporting. For example, Akker et al. (1998) reported that multimorbidity in the Dutch population was associated with low educational attainment and having public (rather than private) health insurance. Huntley et al.'s (2012b) review found 11 studies that reported negative associations between multimorbidity prevalence and a wide range of socio-economic status measures, such as household income, unemployment and social class. All of the studies reported in Violan et al. (2014) that investigated SES gradients found multiple conditions prevalence increased as SES declined. In the UK, both Barnett et al. (2012) and Salisbury et al. (2011) used area-based measures of deprivation in their analyses and showed that multimorbidity prevalence increased with deprivation. To illustrate the deleterious effect of deprivation, Barnett et al. (2012) show how the prevalence of multimorbidity in the most deprived parts of Scotland matches that found among people aged 10-15 years older in the least deprived areas. Moving beyond simply describing its prevalence, two qualitative studies in Scotland have also explored the additional burdens incurred by people with multiple conditions who also face the additional contextual challenge of living in an area of high social deprivation. These studies highlighted both the difficult lives people lead (O'Brien et al. 2014) and the considerable complexity of their treatment needs (O'Brien et al. 2011). Taking a life-course approach, Tucker-Seeley et al. (2011) show how the cumulative impact of adverse socio-economic circumstances, such as financial hardship in childhood, and earnings during young-to-middle adulthood, demonstrate a negative association with multimorbidity onset. Similarly, Tomasdottir et al. (2015) demonstrated an association between retrospective measures of childhood adversity and multiple conditions in adulthood, with allostatic load cited as the possible pathway between these outcomes.

Mortality

The association between multiple conditions and mortality occupies a large portion of the literature, in part due to the links between this and the wider gerontology field. Indeed, a number of comorbidity/multimorbidity indices have been devised with the

specific aim of predicting mortality, such as the Charlson and Elixhauser indices (Sharabiani et al. 2012). Gijsen et al.'s (2001) systematic review showed that most studies using comorbidity indices demonstrated a negative association between comorbidity and mortality. Marengoni et al.'s (2011) systematic review of multimorbidity in the older population included mortality as one of its outcomes, and was similar to Gijsen et al.'s (2001) in terms of the breadth of outcomes investigated. Unlike Gijsen et al. (2001), Marengoni et al. (2011) concluded that the evidence in relation to multimorbidity and mortality was "*controversial*" (p434), with three studies showing a positive association and two finding no increased risk of mortality. However, based on a quality assessment of the reviews, adapted from two checklists (CEBM 2005; CASP 2013), Marengoni et al. (2011) can be shown to have more weaknesses than Gijsen et al. (2001), specifically relating to the search terms used and the number of searching techniques used (see Appendix A for the assessment criteria). For example, there were just five studies specifically reporting mortality outcomes in Marengoni et al. (2011) compared with 36 in Gijsen et al. (2001). Huntley et al. (2012c) reported findings more in line with Gijsen et al. (2001) – all 25 studies, spanning various types of multiple conditions measures, included in their review reported that mortality increased with increasing numbers of conditions. This accumulation of evidence, Marengoni et al. (2011) aside, therefore appears to suggest that the positive association between multiple conditions and mortality is a fairly well established point of consensus in the literature.

Negative experience of health services

In addition to the comparatively larger body of work examining health care utilization by people with multiple conditions – and the associated costs – the ways in which this group often experience sub-optimal health care is a further common area explored in the literature. As already noted, a number of studies have outlined various ways in which people with multiple conditions can be faced with services that are fragmented and time-consuming to use (Hitchcock Noël et al. 2007; Boyd & Fortin 2010; Nobili et al. 2011; Hughes et al. 2013). Salisbury et al. (2011) found that having multiple conditions was negatively associated with continuity of care (despite this being valued by such patients), and concluded that this was a result of the increased number of

consultations made by this group. Liddy et al.'s (2014) review of self-management in the context of multiple conditions also highlighted the difficulties that arise when multiple health care providers give conflicting or confusing advice, adding to the considerable work involved (illness work, as Corbin & Strauss (1985) framed it, is discussed further in Chapter 4). As with the example cited above of unhelpful polypharmacy resulting from systems poorly equipped to coordinate the needs of people with multiple conditions, the appointments systems used in many UK GP practices also appear to ill-serve this group by prioritising rapid access to *any* doctor, over continuity of personnel (Roland & Paddison 2013). Salisbury et al. (2011) also make the important point that attempts to improve mechanisms for sharing information about patients, which they describe as "'*management continuity' and 'information continuity*'" (pe17), do not in themselves help to meet people with multiple conditions' preference for continuity of contact with clinicians. O'Brien et al.'s (2011) study of how GPs and practice nurses manage patients with multiple conditions in very deprived areas sheds further light on the inability of the UK primary care system – as it is currently structured and resourced – to adequately meet the needs of this very complex group; a process they describe in the title of their article as "*an endless struggle*".

The current mechanism for allocating primary care resources is based largely on the size of a local population rather than its actual healthcare needs. This results in the 'inverse care law', a term first coined by Tudor Hart in 1971, whereby: "*the availability of good medical care tends to vary inversely with the need for it in the population served*" (Tudor Hart 1971, p.405). Mercer et al. (2012) argue that the inverse care law amplifies the problems faced by people with multiple conditions because they represent a group with some of the greatest care needs.

Quality of life and wellbeing

As set out in Chapter 1, the analysis presented in this thesis uses measures of wellbeing to elucidate how the experiences of people living with multiple conditions vary. Therefore, this topic is given greater weight in this literature review than is the case with the other areas of emerging consensus described above.

Despite its relatively recent appearance in the research literature, a sufficient number of studies had been conducted in the 1990-2003 period exploring the association between multimorbidity or comorbidity and quality of life for a systematic review to be carried out (Fortin et al. 2004). This widely cited review (86 citations in the PubMed database as of December 2015[7]), found an inverse association between multimorbidity and quality of life in almost all studies that met their inclusion criteria. The study's main limitations, as noted by its authors, included the lack of a consistent definition of multimorbidity, the use of self-reported measures, poor treatment of confounders in the analysis, and the absence of mental-health conditions from most of the studies' multimorbidity definitions – a situation described as "*simply unacceptable*" (Fortin et al. 2004, para. 35). The question of whether self-reported measures are inherently inferior to alternatives such as case-note reviews or administrative data, is less clear-cut than the authors suggest, though obviously has huge implications for the work presented in this thesis, which is based on self-reported conditions. This will be revisited in many of the following chapters.

Similar findings are reported in Gijsen et al. (2001), which reviewed studies of comorbidity between 1993 and 1997. The condition combinations covered by the studies included in this review were generally narrower than was the case in the Fortin et al. (2004) review (as would be expected of a study of comorbidity as opposed to multimorbidity). However, the authors conclude that the majority of studies which utilised a comorbidity index (which is effectively a multimorbidity measure) showed a negative association between comorbidity and quality of life.

More recent studies, many of which have addressed some of the limitations identified by Fortin et al. (2004), have confirmed the original – and expected – finding that multimorbidity is inversely associated with quality of life. For example, Huntley et al. (Huntley et al. 2012b) cite over 20 separate studies of multimorbidity and various measures of quality of life, almost all of which reported an association in the direction expected. Given the almost universal consistency of the findings, it is perhaps

[7] See: http://www.ncbi.nlm.nih.gov/pubmed/15380021 [Accessed 25 December 2015].

surprising that studies of multimorbidity and quality of life continue to be reported. Fortin et al. (2004) justified this body of research by arguing that:

> Although the existence of this association makes logical sense, it still has to be demonstrated and thoroughly studied to find ways of improving care for specially affected patients. Thus, the pressing question may not be whether there is an association but rather how strong is the association and what factors are responsible for it? (Fortin et al. 2004, para. 29).

It is perhaps, therefore, more accurate to conclude that while consensus surrounds the matter of the association between multimorbidity and quality of life, the literature has yet to yield similar agreement on its subtler dimensions, with the question of which specific factors contribute to reduced quality of life so far unanswered. The main consequence of this, of course, is that practical recommendations to improve quality of life among this group of people are somewhat scant. There are, however, examples of work attempting to do more than simply confirm the existence of already established global associations. For example, Lawson et al. (2013) used the 2003 Scottish Health Survey to demonstrate that the negative association between multimorbidity and health-related quality of life (HRQoL) was more pronounced among younger age groups and in those living in the most deprived areas – and described their study as the first to attempt such analysis. Similarly, Mujica-Mota et al.'s (2015) analysis of HRQoL using a survey of GP patients in England also found that outcomes were better among people with multiple conditions at older ages relative to their younger counterparts. They also attempted to explore condition-specific patterns among people with multiple conditions and concluded that people with diabetes, arthritis, neurological or mental health conditions (in combination with other conditions) had the worst outcomes, thus moving the analysis away from the more general findings noted above, and contributing some insights about the potential sub-groups within all those with multiple conditions for whom quality of life might be particularly impaired. Though it should be noted that their data collection method (a postal survey supplemented by a small proportion of online and telephone interviews) yielded only a 38% response rate which, when further item non-response was factored in, meant their final cases available for analysis represented just a 30% response rate. Furthermore, their ascertainment of conditions was fairly limited – based on 12 listed

long-term conditions and an "other" option. Therefore, while their findings are in line with much of the published literature, the likelihood that this study reflects only a partial picture of the overall association between the burden of multiple conditions and HRQoL is quite high.

The literature in this field is, understandably, largely dominated by studies of HRQoL (see the studies included in Huntley et al. 2012b). However, broader, multidimensional conceptualisations of wellbeing exist (Schrank et al. 2013), including the Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS) (Tennant et al. 2007), which has been included in the Scottish Health Survey since 2008. Terminology in this field can be inconsistent, with mental health and mental wellbeing often used as synonyms. However, when developing WEMWBS, Tennant et al. (2007) conceptualised wellbeing as:

> a complex construct, covering both affect and psychological functioning with two distinct perspectives:- the hedonic perspective, which focuses on the subjective experience of happiness and life satisfaction, and the eudaimonic perspective, focusing on psychological functioning and self realization. (para. 2).

WEMWBS underpins one of the Scottish Government's national performance framework indicators (Scottish Government 2015a), and is included in its long-term monitoring of health inequalities programme (Scottish Government 2014), though concerns have been raised about its potential to demonstrate change over time or show much differentiation between groups (Frank & Haw 2011). No analyses of wellbeing using WEMWBS have specifically investigated its association with multiple health conditions. Stewart-Brown et al.'s (2015) analysis of predictors of low and high wellbeing in England covered a range of potential factors but no measures of health, while Wilson et al.'s (2015) Scottish Government wellbeing report only looked at individual CVD and respiratory conditions.

The inclusion of WEMWBS within the Scottish Government's performance framework is illustrative of a wider increase in the significance of wellbeing in research and policy practice in recent years, in many countries. A pivotal stimulus for this was the Commission on the Measurement of Economic Performance and Social Progress,

chaired by the economist Joseph Stigltiz, which argued that measures of subjective wellbeing were important markers of a society's functioning that should be collected by national statistics agencies as well as more traditional economic output measures such as GDP (Stiglitz et al. 2009).

The HRQoL analyses discussed above found outcomes were worse for people with multiple conditions of working age. However, this will, in part, be a function of general age-related patterns in wellbeing. The existence of a U-shaped curve in wellbeing across the lifespan for all adults, with those in middle age showing the lowest levels of wellbeing and those at younger and older ages having the highest, has been widely reported in the wellbeing and happiness literature for some time now (Blanchflower & Oswald 2008). Debate still surrounds the possibility that this pattern might be explained by period or cohort-specific effects, as opposed to changes across the lifecycle that all people undergo regardless of context (Bell 2014). Similarly, Frijters & Beatton (2012) used fixed-effects modelling to argue that the U-shaped pattern is an artefact of reverse causality and selection bias in panel studies (which form the basis of many of reported the U-shaped curve results). Swift et al. (2014) suggest that GDP mediates the association between wellbeing and age (within Europe, at least) such that higher income countries are more likely to demonstrate this U-shaped curve than lower income countries. They argue that this is likely to be due to a wide range of policies that support older people in high income countries, rather than any specific intervention, but this general conclusion nevertheless highlights that external, country-level factors, can be important correlates of older people's wellbeing, rather than it simply being linked to their development of better coping skills over the lifecycle, or revising their views about what they hope to achieve in life's later stages (alternative accounts suggested by Swift et al. (2014), but not tested empirically in their study). Steptoe et al.'s (2014) wider review of the wellbeing literature (focusing on health, ageing and mortality) also concluded that the U-shaped curve was a feature of English-speaking high-income countries, with different patterns evident in all other regions studied (ex-Soviet bloc countries, the Caribbean, Latin America and sub-Saharan Africa). They also suggest that the relationship between health and wellbeing is bi-directional, with poor health reducing wellbeing, and high wellbeing reducing the

impact of poor health. Additionally, they used survival analysis of the English Longitudinal Survey of Ageing to show that higher levels of eudaimonic wellbeing were associated with a higher likelihood of survival in older people, after controlling for obvious confounders such as baseline health status and chronic disease risk factors. Analysis of a German cohort of older adults with multiple conditions found that levels of self-rated health, quality of life and functional capacity were all socially-patterned, with the worst outcomes experienced by those with the lowest incomes; they concluded that differential disease burden could not explain this (von dem Knesebeck et al. 2015).

Conclusion

It is clear that the concept of multimorbidity has become an important research area and is starting to feature in debates about health care delivery and, in the context of policies to manage the burden of NCDs, public health as well. At its core is the recognition that diseases and conditions do not occur in isolation within individuals, and that this needs to be better reflected in how people are treated within healthcare settings, in the design of interventions to improve people's health, and within research more generally. However, conceptual clarity still eludes this field and this hinders attempts to make comparisons of prevalence across time and across settings, and poses challenges for those designing interventions intended to improve outcomes for people with multiple conditions (Smith et al. 2013). This lack of clarity arises from at least two sources. The first, perhaps most fundamental issue, is that what it means to have multiple conditions is not clear-cut and, quite possibly, is not amenable to universal consensus. Whether it should be limited to chronic conditions or should also encompass acute illnesses, or risk factors and other vulnerabilities, are all indicative of the complexity associated with this concept.

The second issue relates to the limits of what can meaningfully be measured. As previously mentioned, in many cases it appears that research in this field has been constrained by pragmatic considerations relating to what data exist, and that multimorbidity has tended to be defined according to what is available to be counted, rather than what would ideally be counted. Many existing data sources, especially those

based on administrative data, can yield only partial measures if multiple conditions is conceptualised very broadly, but if it is very narrowly defined, the availability of data sources expands. The corollary of the need for conceptual clarity about definitions is, therefore, the need for appropriate data to operationalise any such definitions. And if this doesn't exist, then situations where definitions are constrained by data availability should always be made explicit.

The following contrasting approaches to the classification of disease can be found in the diagnosis literature:

> Occam's razor: "entities are not to be multiplied beyond necessity" (Mani et al. 2011 , para. 4)
>
> Hickam's dictum: "patients can have as many diseases as they damn well please" (Mani et al. 2011, para. 8)

While these statements have not been linked to debates about multiple conditions *per se*, they seem particularly apposite in light of the preceding discussion of the definitional difficulties being debated in this field. They also capture, fairly succinctly, one of the key tensions in this field that the analysis presented in this thesis was designed to address.

Chapter 3 Methods, methodology and approach

Introduction

This chapter outlines the methods and approach that underpin the analysis of multiple conditions presented in this thesis. It starts by setting out the research questions, after which a broad overview of population health surveillance is then presented to help locate the quantitative analysis. The next part of the chapter describes the data source in detail, including the specific survey questions and other measures that could be used to identify people living with multiple conditions, with an accompanying commentary on their strengths and limitations. The ontological and epistemological positions that have been adopted for the work are then outlined. Finally, the approach taken to identify conditions for use in the multiple conditions definition is explained.

Research questions

The overarching aim of the work presented in this thesis is to:

- Quantify the experiences of adults living with multiple conditions in Scotland using the Scottish Health Survey.

To address this, the following questions must be answered:

- Does the Scottish Health Survey correctly identify people with multiple conditions?
    - And if not, who is missing?
- How do different definitions of multiple conditions affect its prevalence in the population, and across sub-groups?
- How do experiences of people living with multiple conditions vary in the population?

The quantitative surveillance of population health

Introduction

As the preceding discussions outlined, this analysis hopes to make a contribution to efforts to increase understanding of the nature and experience of the lives of people with multiple conditions in the adult population in Scotland. Its use of population surveillance data warrants a discussion that sites the analysis within this practice and

makes the case for its extension to cover phenomena such as multiple conditions. The following briefly outlines the main role that surveillance plays within public health practice and then places it within the context of Scotland and the rest of the UK.

What is population health surveillance?

The WHO defines population health surveillance as: "*the continuous, systematic collection, analysis and interpretation of health-related data needed for the planning, implementation, and evaluation of public health practice*" (World Health Organization 2015b). As the definition suggests, without knowledge about the nature of a population's disease burden, health service planning would be difficult, strategies to prevent disease (or ameliorate its impact) would be ill-informed and hard to evaluate, and social inequities in its distribution would be hidden. The analysis presented in this thesis uses data collected via a social survey – the Scottish Health Survey (SHeS) – based on interviews with people in their own homes, covering a range of topics including health outcomes and risk factors for poor health (specific details of the survey's methods are presented below). Surveys such as SHeS are just one of a range of tools used to provide population health data; other sources include routine clinical data collected in primary care settings, hospital records, disease registers (such as cancer registries), communicable disease notification systems, Census data collected from whole populations, and general surveys that cover health alongside other topics (Sosin & Hopkins 2006). Many of these sources depend upon the existence of well-developed information-system infrastructures, typical of health systems in the developed world. However, surveys can perform a useful function in countries that lack such systems, supplying the kinds of data that more developed countries would generally obtain from registries (Rothman et al. 2008).

Health surveys are typically categorised as Health Interview Surveys (HIS) if the data collected is purely based on self-reported information from participants, while Health Examination Surveys (HES) also include the direct measurement of items such as height, weight and blood pressure, and can often collect blood, urine and saliva samples (Aromaa et al. 2003). While clinical data have the advantage of having greater validity for some areas of information, such as confirmed diagnoses of conditions, and

sometimes achieve universal coverage, HIS/HESs have the potential to provide a depth and breadth of information about people's lives that could not feasibly be captured in routine clinical encounters (Tolonen, Koponen, Mindell, Männistö & Kuulasmaa 2014). For example, a health survey will typically collect detailed information about people's educational attainment, occupational class, income, health behaviours and well-being, using a systematic approach to data collection and processing, and HESs can sometimes identify undiagnosed conditions or syndromes. An interview can take around an hour, or longer if a health examination is included, which is certainly more time than could feasibly be spent in a clinical setting collecting information from patients purely for research, as opposed to clinical, purposes.

The use of HIS/HES data to track trends over time in health outcomes and risk factors, and to monitor sub-group differences, is widespread in European countries and North America, with their use dating back to the 1950s and 1960s, respectively (Tolonen, Koponen, Mindell, Männistö & Kuulasmaa 2014). In the UK, the multi-topic General Household Survey was the main source of self-reported population-wide health data in the 1970s and 1980s, with data on topics such as long-term conditions, smoking and alcohol consumption collected annually (Office for National Statistics 2013). However, by the early 1990s the need for more detailed information, including examination data, to help monitor and inform health policies led to the commissioning of HESs in England (1991), Scotland (1995), and Northern Ireland (1997) (White et al. 1993; Dong & Erens 1997a; Northern Ireland Statistics and Research Agency Central Survey Unit 2003). Wales has never had a HES, but intermittent HISs have been conducted, largely using postal questionnaires, from 1985 onwards (Nicolaas et al. 2003).

Population surveillance in Scotland

Scotland has a global reputation for high quality, consistent routine health data aided by the long-standing use of a unique patient identifier, the Community Health Index (CHI), in all primary care and hospital encounters, enabling data to be linked and used in research (Health Informatics Research Advisory Group 2015). However, the need to supplement these kinds of sources with data from representative samples of

the public was reflected in the Scottish Office Home and Health Department[8] commissioning its first population health survey (the 1995 SHeS). Plans for SHeS had been set out in the 1992 strategy document *Scotland's Health: A Challenge to Us All*, with the intention of monitoring targets set out in the 1991 *Health Education in Scotland: A National Policy Statement*, and the dietary targets published in 1994 (Dong & Erens 1997a). Although these targets span a broad range of health topics, the survey's founding overarching purpose was the investigation of risk factors for cardiovascular disease, a major source of morbidity and mortality in Scotland. The survey was repeated in 1998 and 2003, before switching to a continuous format from 2008 onwards. At present, it is the only source of regular population-wide data on: dietary habits, physical activity, alcohol consumption (as opposed to purchases), wellbeing, BMI, and long-term conditions. It is currently used to monitor progress towards more recently set targets such as those in the *Obesity Route Map* (Scottish Government 2010), the Scottish Government's *National Performance Framework* (Scottish Government 2015b), and its *Long-term Monitoring of Health Inequalities* program (Scottish Government 2014).

Population surveillance of multiple conditions

Chapter 2 outlined the recent emergence of the concept of multiple conditions in research and practice, and noted the population prevalence study conducted in Scotland using primary care data from 314 GP practices in 2007 (Barnett et al. 2012). SHeS participants are asked to report information about long-term conditions and, as will be detailed further below, other aspects of their health and behaviours that can, collectively, be used to estimate the prevalence of multiple conditions. The current reporting of multiple conditions in SHeS is limited to the information solely collected at an unprompted question on long-term conditions, with no use made of the wider health and conditions data available. This omission served as the starting point for this analysis, with my concern to "improve" the measurement of multiple conditions fuelled in part by a desire to see more accurate reporting, but also a concern to make

[8] Following devolution in 1999, responsibility for the survey lay with the new Scottish Executive Health Department, followed by the Scottish Government Health Directorate in 2007, and the Health and Social Care Directorate in 2010.

full use of the information that participants volunteer during the course of what is a fairly extensive data collection exercise.

While disease prevalence estimation is an important element of health surveillance, self-reported measures have limitations (as detailed more below). Therefore, arguably the most useful contribution that a source such as SHeS can make to this field is to shed light on the wider life circumstances and experiences of people living with multiple conditions. One of the main strengths of a multi-topic population health survey is its ability to connect the dots between people's health outcomes, risk factors and wider social circumstances. For example, work on multiple risk exposures reveals how many of the objects of public health interventions such as smoking, poor diet or low physical activity are in fact inter-connected and cluster within the same individuals (Lawder et al. 2010; Bromley 2011).

While a survey can never capture the depth and complexity of experiences that qualitative studies such as those reviewed in Chapter 2 can (O'Brien et al. 2014), it can provide complementary information about the extent of particular configurations of experience, the nature of the social patterning of those experiences, and, in some cases, their change over time and link to later outcomes. To ignore the potential of such analyses to reflect the circumstances of a group (in this case people with multiple conditions) that is attracting increasing attention in policy and practice circles, and for whom interventions are being developed, would be remiss. It would also represent a failure to maximise the use of data that has been collected at considerable public expense – both in terms of its financial costs and time burden on participants. Furthermore, data such as this can also contribute to more critical debates about the utility of concepts such as multiple conditions, and challenge some of the orthodoxies that surround it.

The following section describes the methods used in SHeS and expands on some of the strengths and weaknesses already highlighted.

The Scottish Health Survey

Study overview

The survey was first run in 1995 and was repeated on an intermittent basis, in 1998 and 2003, before switching to a continuous mode from 2008 onwards. Although the core aims and design have remained broadly similar since its inception, notable changes were introduced in 2008 and 2012, hence the grouping of the following description around those periods. Children have been included in the survey from 1998 onwards; however, as the analysis presented here is based only on adults, information about the sampling and data collection methods related to children has been omitted. The following discussion uses information from the published technical reports available for each survey year, as well as personal knowledge gained from my role as project manager, then director/principal investigator, from 2002 until 2012. The published sources are as follows:

- 1995: Dong & Erens (1997b).
- 1998: Shaw et al. (2000a).
- 2003: Bromley et al. (2005).
- 2008-2011: Bromley et al. (2009; 2010; 2011); Rutherford et al. (2012).
- 2012: Rutherford et al. (2013).

1995-2003

As noted above, SHeS was launched in 1995 as a study of the working-age population (16-64), living in non-institutional establishments in Scotland (typically referred to in UK survey sampling as the "household" population). It was initially intended to be repeated on a three-yearly basis (in contrast to the annual continuous survey conducted in England from 1993 onwards). When it was repeated in 1998 the upper age limit increased to 74. Following a five-year gap, it was next conducted in 2003, at which point the previous age-related sample restrictions were removed. The core features of the study were broadly similar in this period: interviewers conducted the main interview and measured height and weight, while nurses conducted the health examination element, and collected and coded information on prescribed medicines.

2008-2011

The study underwent a major re-design prior to switching to a continuous format in 2008. The sample population stayed the same (0+), but to save costs the nurse examination element was restricted to a sub-sample of around one in six adult participants (16+) (described as the "nurse sample" in subsequent discussions). The 2008 to 2011 surveys were designed to enable pooling of multiple years' data to provide more precise estimates for sub-groups, such as Health Boards and the 15% most deprived areas, after either two or four years had accrued. A modular structure was introduced to expand the range of topics covered in the interview, with certain topics asked in alternate years, rather than annually.

2012 onwards

Further modifications were introduced from 2012 onwards. Most of the design elements introduced in 2008 were retained, including the capacity to pool years of data (e.g. 2012-2013, 2012-2015, but not across the time periods before and after 2012). The biggest change saw specially trained interviewers replace nurses to collect biomarker information, which resulted in some of the information and samples collected changing. Of most relevance to this work was the loss of blood samples and prescription medication coding.

Sample design

The sample source for all surveys was the Postcode Address File (PAF), a list of all UK addresses to which Royal Mail makes deliveries. Multi-stage random probability sampling was used, with regional stratification and clustering of addresses to make fieldwork more efficient. The stratification and clustering methods differed across the years, as explained below. Interviewers were issued with batches of addresses and tasked with identifying invalid ones, such as empty or derelict properties, businesses and communal accommodation (e.g. halls of residence, care homes). At addresses occupied by more than one household, interviewers made a random selection, using a

pre-supplied Kish grid.[9] Again, while these core sampling features are common to all survey years, various changes have been introduced across the years.

1995 and 1998

The 1995 and 1998 sample was stratified by seven regions comprising pairs of NHS Health Boards (Greater Glasgow was its own region, Highlands was paired with all the Island boards), and by area deprivation (using the Carstairs Index (ISD Scotland 2010b)). A sufficient number of addresses was selected in each of the regions to enable estimates to be made at this level.

A multi-stage design was used to select households, with geographic localities selected as the primary sampling units (PSU) and batches of addresses then selected within each PSU (households were selected as described above). This method ensured that interviewers' assignments could be covered more efficiently (without the first stage, addresses would have been scattered across regions often with very large distances between them). However, it introduced clustering to the sample whereby the participants could be more similar to each other in certain characteristics (for example, their socio-economic status) than would be the case if a simple random sample had been drawn. Clustering increases standard errors for estimates, but this can be taken account of in the analysis (Groves et al, 2009).

One adult (16 years and over) per household was selected at random to take part, again using a Kish grid.

2003

The regional and deprivation stratification approach used in 1995 and 1998 was also used in 2003. However, to reduce the number of addresses at which interviews were conducted (and thus reduce costs), from 2003 onwards the selection of adults changed, so that all adults (up to a maximum of 10) in selected households were eligible to be interviewed. While this method introduces further clustering at the

[9] A Kish grid is a randomly generated table of numbers. Interviewers list the elements to be sampled (households, adults or children) in a standardised format (e.g. adults in descending order of age, or in alphabetical order), and use the Kish grid to determine which of the listed elements should be selected. Kish grids minimise the potential for selection bias to be introduced. Quality control spot checks monitor the accuracy of their administration.

household level, it also enables the analysis of within-household health and behaviour patterns.

2008-2011

The sampling procedures introduced in 2003 remain in place to date, however the seven region stratification was replaced with a design that enables estimates to be made for each of Scotland's 14 regional Health Boards, and the 15% most deprived areas. The deprivation-based stratification used the Scottish Index of Multiple Deprivation, which was launched in 2004 (ISD Scotland 2010c). The very small (and dispersed) populations in some of the Health Boards (e.g. ~23,000 in Shetland, ~27,000 in the Western Isles (ScotPHO 2015c)) would make it very expensive, and logistically challenging, to provide these estimates annually. Instead the sample was designed to be pooled across four years, with a target minimum achieved sample size in each board.

As described above, the 1995-2003 sample used a clustered design, with batches of addresses grouped at the local level. The 2008-2011 sample was designed to provide geographically unclustered estimates using the pooled sample, though clustering was still present in the single years' surveys (and household member clustering remained). The analysis of 2008-2011 data presented here has not, therefore, needed to take account of design effects due to geographic clustering.

The pooled sample also enables analysis of subgroups that are typically small in the population; the majority of the analysis presented in this thesis uses the 2008-2011 pooled sample and takes advantage of the large sample this provides.

Data collection methods

The data collection methods and record-linkage have been broadly similar in all surveys, in part due to the need to maintain comparable data for time series estimates. The majority of the data are collected via a face-to-face interview conducted in participants' homes, using computer assisted personal interviewing (CAPI). From 2003 onwards (when multiple household member sampling began) up to four people could be interviewed concurrently in one interview session. This has clear implications for

the health status and conditions questions, as participants could be reluctant to disclose diagnoses of some conditions in front of other household members.

Some very sensitive topics, such as problem drinking, the General Health Questionnaire (GHQ 12) (Goldberg & Williams 1988) and, from 2008, the Warwick Edinburgh Mental Wellbeing Scale (WEMWBS) (Tennant et al. 2007) are included in a supplementary paper self-completion, administered during the interview. Young adults (aged 16-18 years, and in some cases, 18-19 years) answer questions about smoking and drinking via the self-completion, rather than face-to-face.

Adults provided answers on their own behalf with no proxy interviewing permitted, for example in the case where someone did not have the capacity to consent to being interviewed, or if a selected participant was absent. This means that the survey under-represents adults with mental incapacity, for example older people with dementia, which is a notable weakness of the methods used.

Survey response

Response rates for the surveys on which this analysis is based are shown in Table 3.1. Note that the change in sample design after 1998, described above, introduced additional levels of non-response and extended the population covered (age 75 and over), both of which reduced response rates, though also made them difficult to compare over time.

Table 3.1 Scottish Health Survey adult participant response rates, 1998, 2008-2011

	1998 (16-74 years)	2008-2011 (16+)
Addresses sampled	15,332	32,830
Total households in scope	11,836	29,580
Households in which at least 1 adult interviewed	9047 (76%)	18,797 (63%)
Households in which all eligible adults interviewed	n/a	14,685 (50%)
Total adult participants	9047 (76%)	28,785 (55%)
Nurse sample		
Nurse visit conducted	7455 (63%)	4273 (31%)

Health-record linkage

Consent to link participants' survey data with their NHS health records has been sought since the survey began. The 1995-2011 consent covers secondary care data (hospital episodes), cancer registrations and mortality (Gray et al. 2010); from 2012 consent to link to primary care data has also been included (though such data are, at present, unavailable). The 1995 and 1998 surveys used verbal consent, from 2003 signed consent was obtained. Rates of consent have been very high (92% in 1998). Table 3.2 shows that small, but statistically significant, differences in consent permission rates exist by age and area deprivation. However, while people with very bad self-assessed general health had the lowest consent rates, the difference was not significant (this group is very small).

Table 3.2 Consent to NHS record linkage by age group, area deprivation and self-assessed health, 1998 SHeS

	Consent to linkage[a]	
Age (p<0.001)[b]	%	***Sample size***
16-24	93	*1385*
25-34	93	*1894*
35-44	93	*1817*
45-54	93	*1578*
55-64	91	*1268*
65-74	89	*1053*
Area deprivation quintile (Carstair's index) (p<0.001)		
1st most deprived	90	*2445*
2nd	92	*1967*
3rd	93	*2083*
4th	92	*2230*
5th least deprived	93	*2405*
Self-assessed health (p=.147)		
Very good	92	*4586*
Good	92	*4353*
Fair	92	*1670*
Bad	92	*433*
Very bad	84	*87*

[a]All figures are unweighted.

[b]p values are based on the chi-squared test for trend.

The linked data are held by the Information Services Division (ISD) of NHS Scotland, who oversee applications for access to the data. A minimum dataset with general and mental health acute/in-patient day cases, cancer registrations and mortality records is

available for use with minimal restrictions. Other data items, such as maternity records or outpatient visits, require additional safeguards for their use. The analysis presented here uses the 1998 minimum linked dataset (the application for use is provided in Appendix C).

Health condition questions and coding

Long-term conditions - unprompted

Question wording

The question wording used in 2008-2011 to collect information on people's long-term condition (LTC) status was as follows:

> *Do you have a long-standing physical or mental condition or disability that has troubled you for at least 12 months, or that is likely to affect you for at least 12 months?*
>
> *[IF YES]*
> *What is the matter with you? {Free text entered by interviewers}*
>
> *Does [name of condition provided] limit your activities in any way? {Yes / No}*

It was intended to measure long-term conditions and disabilities, without any initial prompting about what conditions should be included, beyond the stipulation about their duration. Interviewers were tasked with recording the details of conditions mentioned, using probes where appropriate (as outlined in Figure 3.1). The same looped format and follow-up questions were used in 1998 and 2003, however the initial stem of the question differed:

> *Do you have any long-standing illness, disability or infirmity? By long-standing I mean anything that has troubled you over a period of time, or that is likely to affect you over a period of time?*

The question wording was revised for the 2008-2011 survey due to concerns that the lack of a defined time period could lead to participants interpreting it inconsistently, and that mental health conditions were being under-reported. As a consequence, the estimates of long-term conditions based on these questions are not directly comparable

over time, but they are, however, sufficiently close to be deemed functionally equivalent for the purposes of the analysis presented here.

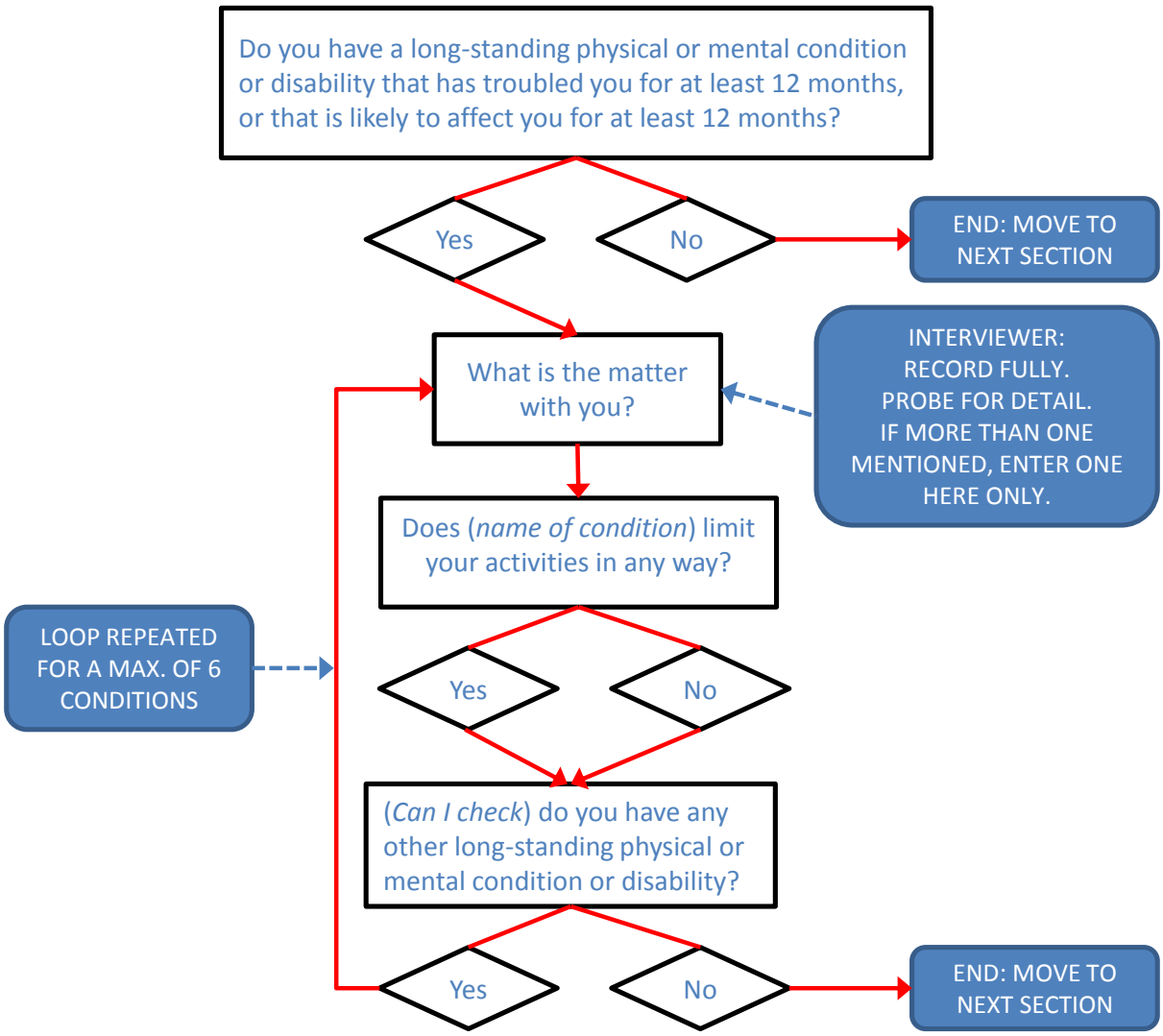
At present, all published estimates of the prevalence (Given 2010) or impact (Lawson et al. 2013) of multiple conditions based on SHeS use the information collected at this question, and no other data.

Before being asked the long-term conditions question, participants were asked to self-assess their general health status, using a long-established measure common in health surveys:

> *How is your health in general? Would you say it was …very good, good, fair, bad, or very bad?*

While this question does not produce information about specific named conditions, it is a helpful benchmark of subjective health status and has been shown to be a good predictor of service use, morbidity and mortality, and is an important marker of health inequalities (Jylhä 2009; Au & Johnston 2014). It also likely to have helped frame people's thinking when they responded to the question (and its associated follow-ups) on long-term conditions and disabilities.

Figure 3.1 Flowchart of long-term conditions question, SHeS 2008-2011



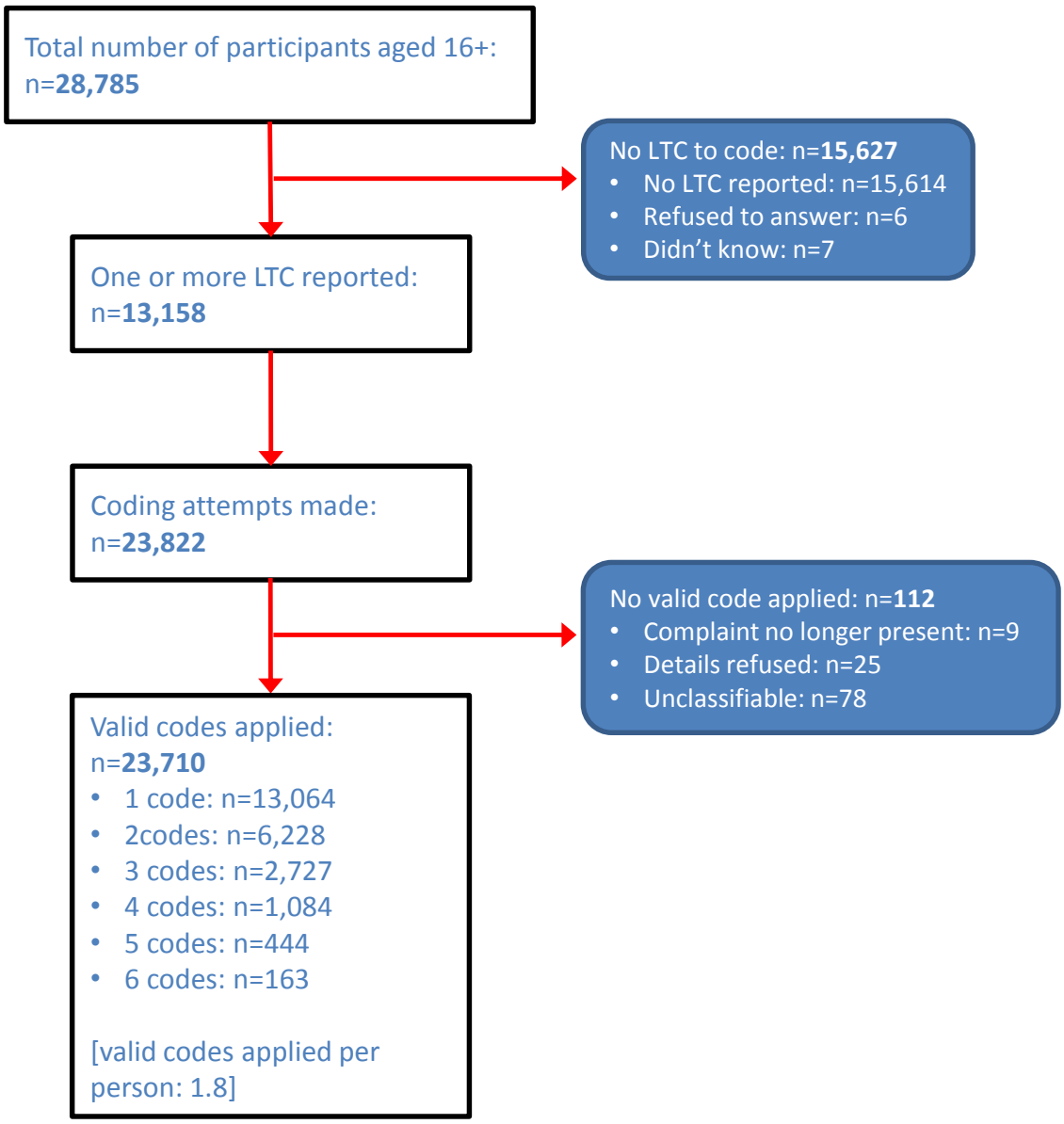
Coding

The LTC question, as originally designed, was intended to measure the overall burden of long-term conditions in the population, and the relative contributions made by conditions related to specific body systems. It was not designed to be a measure of specific individual conditions or, therefore, multiples of them. The coding methodology therefore needs to be understood in terms of those original objectives.

The free text data from the LTC question was processed by a centralised team of coders overseen by the NatCen Social Research Operations Department (see Figure 3.2 for an overview of the process). A code frame with 40 categories was used (see

Appendix D for the coding instructions and the full codeframe). Some of the codes covered very specific conditions, such as diabetes (though no distinction was made between types 1 and 2), whereas others captured a very wide range of related conditions, such as neoplasms, lumps and cysts (malignant and benign). The codeframe was originally designed for use in the 1988 UK General Household Survey to enable the reporting of condition types based on a selection of 15 ICD chapters (see Table 3.3, ICD-9 was in use when it was developed, but the chapter structure is broadly similar for ICD-10, if not the numbering). The unprompted LTC question (and the specific CVD condition questions described below) were inherited from the 1994 Health Survey for England (HSE), on which the first SHeS (in 1995) was largely based (Shaw et al. 2000b). In turn, the HSE long-term conditions question was taken from the UK-wide General Household Survey (GHS), conducted by the Office for National Statistics (ONS) since 1971 (White et al. 1993). Although the GHS interviewers recorded information about conditions in the same way as the HSE and SHeS, the data were not routinely coded (it was described as a "*courtesy question*" (White et al. 1993, p.212)). However, a long-term conditions codeframe was developed for the 1988 and 1989 GHS, as described above, and that methodology – largely unchanged – remains in use by SHeS today.

Figure 3.2 Flowchart of long-term condition (LTC) coding process, **SHeS 2008-2011**



ICD is designed primarily to capture information about causes, as opposed to symptoms, so certain accommodations had to be made to use it with this data. For example, some ICD chapters were omitted as they do not relate to long-term conditions (such as pregnancy, childbirth and the puerperium, ICD-10 chapter 15), or because they relate wholly to causes with no reference to body-systems (external causes of morbidity and mortality, ICD chapter 20). Similarly, congenital conditions were coded using the corresponding body-system chapter for the reported condition, rather than under a single code for all such conditions (as per ICD-10 chapter 17), because of

the difficulty of establishing whether participants had their condition at birth or acquired it later (White et al. 1993).

Table 3.3 Condition codes by ICD 10 chapter number (and sub-groups, where applicable), SHeS 2008-2011

ICD 10 chapter number	SHeS condition code
1) Infectious disease	37
2) Neoplasms and benign growths	1
3) Blood & related organs	38
4) Endocrine & metabolic	
-Diabetes	2
-Other endocrine/metabolic	3
5) Mental disorders	
-Mental illness/anxiety/depression/nerves	4
-Learning disability	5
6) Nervous system	
-Epilepsy/fits/convulsions	6
-Migraine/headaches	7
-Other problems of the nervous system	8
7) Eye complaints	
-Cataract/poor eye sight/blindness	9
-Other eye complaints	10
8) Ear complaints	
-Poor hearing/deafness	11
-Tinnitus/noises in the ear	12
-Meniere's disease/ear complaints causing balance problems	13
-Other ear complaints	14
9) Heart, blood vessels & circulatory system	
-Stroke/cerebral haemorrhage/cerebral thrombosis	15
-Heart attack/angina	16
-Hypertension/high blood pressure/blood pressure	17
-Other heart problems	18
-Piles/haemorrhoids	19
-Varicose veins/phlebitis in lower extremities	20
-Other blood vessels/embolic	21
10) Respiratory system	
-Bronchitis/emphysema	22
-Asthma	23
-Hayfever	24
-Other respiratory complaints	25
11) Digestive system	
-Stomach ulcer/ulcer/abdominal hernia/rupture	26
-Other digestive complaints (stomach, liver, pancreas, bile ducts, small intestine – duodenum, jejunum & ileum)	27
-Complaints of bowel/colon (large intestine, caecum, bowel, colon, rectum)	28
-Complaints of teeth/mouth/tongue	29
12) Skin complaints [39]	39

Table 3:3 Condition codes by ICD 10 chapter number (and sub-groups, where applicable), SHeS 2008-2011 (continued)

13) Musculoskeletal system	
-Arthritis/rheumatism/fibrositis	34
-Back problems/slipped disc/spine/neck	35
-Other problems of bones/joints/muscles	36
14) Genito-urinary system	
-Kidney complaints	30
-Urinary tract infection	31
-Other bladder problems/incontinence	32
18) Other complaints	40

As can be seen, some conditions were assigned chapter-level codes (e.g. infectious disease, skin complaints), with no further distinctions made between the conditions reported (e.g. eczema, chronic acne). In the majority of cases, however, conditions were assigned sub-chapter level codes.

Coders could allocate a maximum of six separate codes for LTCs (in accordance with the original questionnaire design that enabled interviewers to record six LTCs). If an interviewer had entered two conditions in one data entry field (rather than in two separate ones, as instructed), the editor could correct this and assign two codes, providing the maximum of six was not exceeded. Many of the codes cover a number of different conditions, so people could end up with the same code applied more than once. Code 4, "mental illness/ anxiety/ depression/ nerves", was one of the most common to be applied more than once (e.g. someone reporting depression and alcoholism, or depression and anxiety, could receive two code 4s). The consequences of this aggregation are discussed further in Chapter 5.

The data were then subject to two stages of aggregation when they were processed. The first combined the multiply coded conditions (such as depression and anxiety) so they were only counted as one condition. The second stage mapped the 40 condition codes onto their 15 corresponding ICD chapter headings. During this process, codes such as arthritis (34), back problems (35) and other muscle / joint conditions (36) were combined to form the group representing "Musculoskeletal system conditions". This aggregation was carried out on the grounds that the conditions with the same codes, or within the same chapters, were very similar and, consequently, no guarantee could be

made that the information provided by participants and recorded by interviewers, was sufficiently detailed to enable them to be considered wholly accurate measures of distinct conditions. For example, given the nature of the way the data were collected, coding discrepancies could quite commonly occur within some chapters, such as within the musculoskeletal chapter, with arthritis in the neck coded 35 (back problems/ slipped disc/ spine/ neck) rather than 34 (arthritis), depending on how participants reported their condition and/or interviewers recorded it. In contrast, errors across chapters (e.g. arthritis being coded as a mental health condition) should be much less common, due to the training and supervision coders undergo, and the quality assurance checks employed. The designers of this process therefore decided that reporting at the level of ICD chapters, rather than individual reported conditions, would minimise the impact of these kinds of errors on prevalence estimates (White et al. 1993).

The summary measure of the number of long-term conditions reported that is provided in the SHeS dataset (and other surveys that use this coding method, such as the HSE or GHS) is based on these grouped, chapter-level codes, rather than the underlying conditions people reported. Its adequacy as a measure of multiple conditions – as opposed to a measure of individual condition types – is therefore potentially impaired by these two stages of aggregation.

Quality of the information collected

The conditions reported could not be verified externally, for example by cross-checking primary care data. This, of course, raises questions about their accuracy, due to people under-reporting conditions (for various reasons), or mentioning symptoms that had never been formally diagnosed as a specific condition (see the discussion of potential resulting biases, and steps taken to minimise them, below). However, the anonymised free-text answers to the LTC question were made available to me for this analysis so the recorded information and coding applied could be assessed. Reviewing these answers revealed quite a high degree of variability in the extent of interviewers' probing, as reflected in the depth of information provided. For example, some

interviewers probed[10] to find out if a participant was taking medication for their condition, or the time since diagnosis, while others simply noted the names of the reported conditions (with a variety of interesting spellings), often in very broad terms, e.g. "mental health condition". However, while variable, the quality of the information collected appears to have been sufficient for its intended purpose – just 112 LTC (<1%) answers were judged unclassifiable. This is perhaps unsurprising, given the breadth of some of the categories within the codeframe, which means that a very general description such as "mental health condition" provides sufficient information to enable the correct code to be assigned (a specific named condition, such as "schizophrenia", is not necessary). This is arguably a clear example of the data being as good as it needed to be; the challenge comes when trying to put them to uses they were not originally intended to have – i.e. the identification of discrete conditions in order to estimate the extent of *multiple* conditions.

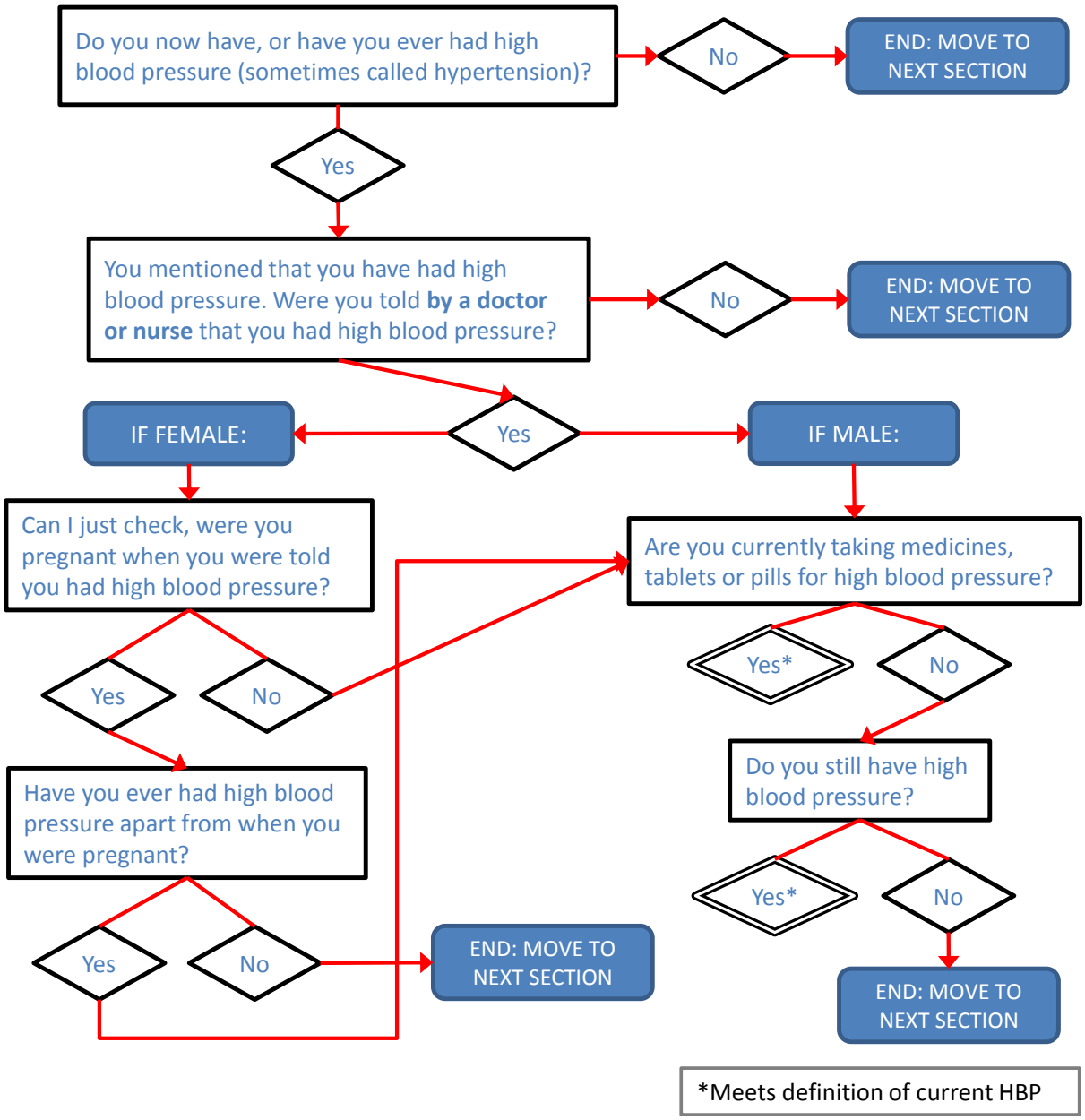
Specific named conditions

Question wording

Ever since it began, the survey has also included a series of detailed questions about specific named cardiovascular system conditions (angina, heart attack, heart murmur, abnormal heart rhythm, other heart problems), stroke, hypertension and diabetes (from here on in described as the "CVD questions", though stroke and diabetes are, of course, cerebrovascular and endocrine system conditions, respectively). If any of these conditions were reported, participants were asked whether a doctor (or nurse, in the case of hypertension) had diagnosed it. For CVD or stroke events/onset, participants were asked if these occurred within the previous 12 months or longer ago. Questions were also asked to identify gestational-only cases of diabetes and hypertension, while further questions established if these conditions were currently being treated (and how) (see example of hypertension in Figure 3.3 below).

[10] Some interviewers, generally those with more years' experience or advanced training, mark their text with // to indicate that they had probed further, and /- to signal the point at which that no further information was forthcoming from the participant.

Figure 3.3 Flowchart of questions intended to measure current hypertension prevalence, SHeS 1998, 2008-2011



Other health problems

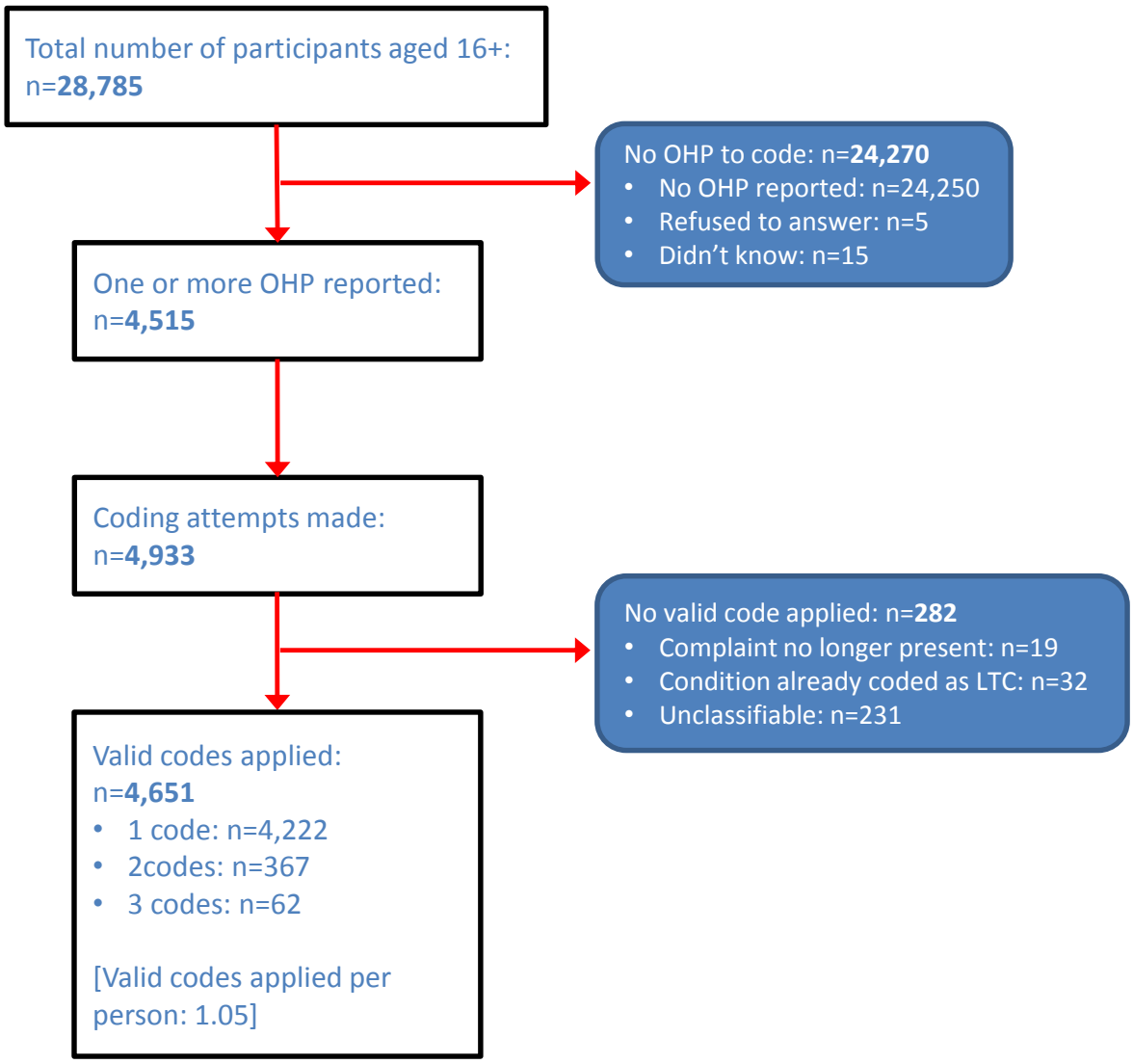
Question wording and coding

SHeS includes an additional question at the end of the section on cardiovascular conditions which asks:

Can I check, do you have any other health problems that I have not asked you about? *(If yes)*

The original justification for its inclusion in 1995 is unclear, the data do not appear to have ever been used, and neither the HSE nor GHS ask this. Interviewers recorded the details of any other health problems participants mentioned, but unlike the long-term conditions question, no further details about their impact on daily life were collected. The answers were coded in the same way as those given for the LTC question, using the same code-frame (see Figure 3.4 for details, and codeframe in Appendix D). These data were something of a mystery: a binary variable recording the presence of other health conditions is included in the public SHeS dataset every year, but the coding applied to the reported conditions is not, and, in common with the long-term conditions questions, the free-text information recorded by interviewers is not publicly available, because of its potentially disclosive nature. Therefore, the nature of the issues reported at this question, and whether they should be included in the multiple conditions measure, was unclear. They could be transient, short-term issues (e.g. a bout of the 'flu); intermittent conditions but recurring, such as migraine or hay-fever; or perhaps conditions that participants had forgotten to mention, or had been reluctant to mention, earlier on in the interview when asked about long-term conditions. To help answer these questions, access to the free text data was granted alongside the information provided about long-term conditions.

Figure 3.4 Flowchart of other health problem (OHP) coding process, SHeS 2008-2011



Biomarkers of underlying conditions

Height and weight

Interviewers measured height and weight following standardised protocols (see Appendix B of: Rutherford et al. 2012). Height was measured in centimetres (to the nearest even millimetre) using portable stadiometers. Weight was measured using electronic scales in kilograms (to the nearest 100g). Participants who weighed over 130kg, those who couldn't stand, pregnant women and those who did not wish to be measured, were excluded. Interviewers were asked to record if problems occurred during measurements and, if so, these data were excluded from the analysis. Scales

were calibrated on a regular basis throughout fieldwork, and measurement protocol adherence was monitored during fieldwork supervisions.

The height and weight data were used to estimate participants' body mass index (BMI) – height in cm / weight in kg^2. The thresholds used to classify BMI were: underweight (<18.5 kg/m^2); healthy weight (18.5-<25 kg/m^2); overweight (≥25-<30 kg/m^2); obese (≥30 kg/m^2).

Blood pressure

Nurses measured blood pressure during a separate, follow-up interview, using Omron HEM207 devices. Three readings were taken at one minute intervals, following a five minute rest period. Pregnant women were excluded from the measurements. The analyses presented in this thesis are based on the average of the final two measurements (if all three were obtained). Readings from people who had eaten, drunk, exercised or smoked a cigarette in the 30 minutes prior to the readings were excluded.

Blood samples

Non-fasting blood samples were collected by nurses via venepuncture. People were excluded from providing a blood sample if they were pregnant, taking anti-coagulant drugs, or had a history of fitting. Samples were dispatched to the survey laboratory for analysis at the Royal Victoria Infirmary, Newcastle. The analyses presented in this thesis use the results of the glycated haemoglobin (HbA1C) and total cholesterol analytes. People who were known to be taking lipid-lowering drugs (e.g. statins) that reduce cholesterol were excluded from the analysis. The quality control procedures for the analytes are described in Roth et al. (2012).

Prescription medication data

Nurses collected the names of all prescribed medications participants reported taking (recording details directly from containers where available) and asked whether they had been taken within the previous 7 days. Nurses also applied British National Formulary (BNF) coding to the information collected (British National Formulary 2009). Additional questions were asked about any drugs with BNF codes beginning 02

(cardiovascular system drugs) to establish if they were being taken to treat high blood pressure, heart problems or for other reasons. The prescription data and blood pressure readings were used in combination to establish the prevalence of untreated hypertension in the population.

Psychological distress measures

The General Health Questionnaire 12 (GHQ12)

The 12-item GHQ has been included in every SHeS since it began. It was designed to measure symptoms of psychological distress in the form of deviations from usual functioning in the previous few weeks (the full questionnaire is in Appendix E). The areas covered include concentration; sleep; feelings of: usefulness, capability, strain, unhappiness, depression, worthlessness; the ability to overcome strain and overcome problems; enjoyment of normal activities; and self-confidence. Responses use a four point scale to which points are assigned. Scores range from 0 to 12, with a threshold of 4 or more commonly used in population research to identify someone with a potential psychiatric condition (Goldberg & Williams 1988). The use of such measures in surveys is discussed in more detail in Chapter 4. As noted above, the GHQ12 was presented to participants as a paper self-completion during the main interview, due to the sensitive nature of its questions.

The Revised Clinical Interview Schedule (CIS-R)

A subset of items from the CIS-R was included in the 2008-2011 nurse interview (Lewis et al. 1992). Their fairly complex routing made them unsuitable for a paper questionnaire. It was decided that nurses were better placed to administer the questions as these interviews were conducted without other household members present (where possible) and nurses were judged to be better placed to handle any difficulties arising from their content. The questions covered symptoms of depression and anxiety, suicide attempts and self-harm. The full question text is contained in Appendix E.

Survey limitations and biases

A significant literature exists on the limitations and resulting biases associated with population surveys, some of which is referenced below. Rather than review the survey

method in its entirety, some key points have been selected that relate directly to the primary focus of the analysis presented – the measurement of multiple conditions and related experiences.

A critical distinction can be made between the information this – and any – survey *intends* to collect and what, in reality, it *succeeds* in collecting. The main, but by no means only, causes of the gap between these two factors are error and bias. No survey avoids these; the key challenge is to minimise their impact and thus constrain the size of the gap between the survey's intended and actual outcomes.

There are at least two types of limitations and resultant biases that are useful for this discussion: firstly, those inherent to all surveys, and secondly, those specific to the data collected on health conditions – though the two often overlap or are interrelated. For example, excluding adults with mental incapacities is a problem inherent to all population surveys that rely on participants providing their own responses, rather than being "spoken for". This limitation has particular resonance for health surveys as it effectively introduces a health-related exclusion bias, leading to an underestimation of a population's illness burden. Similarly, participants' reluctance to disclose sensitive information is a feature of any survey covering sensitive topics, however the fact that some conditions fall into this category will also lead to an underestimation of poor health in a population.

The potential source of bias that tends to be most associated with surveys, and often provokes most concern, is non-participation. For example, Rothman, Greenland and Lash (2008) describe the maintenance of high response rates as "*the single largest obstacle to high-quality epidemiologic research*" (p.497). Survey response rates are generally declining in most countries, and health surveys, including SHeS (see Table 3.1), have not been immune to this trend (Aromaa et al. 2003; Galea & Tracy 2007; Rothman et al. 2008; Meyer et al. 2015). However, the relationship between response rates and bias is not completely straightforward: rates can decline without increasing bias, while it is also possible for increased response rates to produce more biased estimates if the additionally recruited participants are atypical (Groves 2006; Groves & Peytcheva 2008; Davern 2013). Gorman et al. (2014) analysed the impact of non-response on

estimates of alcohol-related deaths and hospitalisations using the 1995-2010 SHeS. They found that rates of these outcomes were higher in the general population than among survey participants, confirming other studies that have showed non-participants to have worse health behaviours and poorer outcomes. However, they also found no evidence that the extent of the bias has increased over time, despite lower response rates (and declining record-linkage consent) in recent years. Similarly, Meyer et al.'s (2015) analysis of declining response in household surveys in the US concluded that non-participation, as a source of bias, actually contributes far less to errors in overall estimates than participants' failure to answer items within surveys, or to answer them accurately, does (largely due to the corrective properties of unit nonresponse weighting).

Response rates are just one potential source of bias in surveys. The Total Survey Error (TSE) framework (Biemer 2011) provides a comprehensive way of assessing a survey's performance, encompassing multiple sources of errors related to: the study's initial specification, measurements, frame (i.e. the sample frame coverage), nonresponse and data processing. The sources of such errors can be traced to the performance of the interviewers, participants and – in some cases – the coders who work with the data after they have been collected. Often (but certainly not always) such problems can be prevented, minimised or at least corrected for, post-hoc. The complete elimination of error is, however, a Sisyphean task, and Biemer (2011, p.821) instead suggests surveys should strive: "*…to avoid the most egregious errors and control other errors to the extent that remaining errors are mostly inconsequential and tolerable*."

Some examples of error sources that relate specifically to this analysis, and the TSE domain they occupy, are presented in Table 3.4 (frame error has already been mentioned above, in relation to the exclusion of adults without capacity to consent). Looking at the measurement of multiple conditions through the TSE lens suggests a number of ways in which the survey's current measures might not paint a wholly comprehensive picture, and which warrant further investigation. These themes are therefore revisited in Chapter 5, which assesses the survey's health questions and their suitability for inclusion in the multiple conditions measure.

Groves and Lyberg (2011) extend the TSE framework to include the issue of relevance and usefulness, pointing out that a statistic can be accurate but irrelevant, with relevance defined according to whether users' needs have been met by the measure in question. This issue lies at the heart of much of the analysis presented in this thesis. It is not sufficient to improve the accuracy of a multiple conditions measure, the question of its usefulness should also be addressed.

Table 3.4 Assessment of selected limitations and biases within the Scottish Health Survey, and proposed remedial strategies, using a Total Survey Error (TSE) approach

TSE domain and potential limitation	**Potential bias**	**Steps to reduce bias routinely taken as part of the survey's conduct**	**Additional strategies that could be taken (text in bold indicates the steps explored in this thesis)**
Response error: Some participants refuse to be interviewed	Depends – if participating and non-participating people have identical characteristics (age, sex, health status, SES) then no bias should arise. If response differs across groups, and is related to key survey measures (such as health) then estimates will be inaccurate. For example, response declines as deprivation increases (though is also low among the most affluent areas), and health is known to decline as deprivation increases.	1998: non-response weighting at household level to adjust the profile of participants to better resemble the target population; additional sample issued in the final quarter of fieldwork (Shaw et al. 2000a). 2008-2011: non-response weighting at household and individual level; participant incentives (£5 shopping voucher per participating household); additional sample issued in 2009-2011 to address lower than expected response in 2008 (Rutherford et al. 2012).	N/A

TSE domain and potential limitation	Potential bias	Steps to reduce bias routinely taken as part of the survey's conduct	Additional strategies that could be taken (text in bold indicates the steps explored in this thesis)
Response error: Interview is more burdensome for people with health conditions than those without (more questions to answer, more risk factors to report).	Non-response might be higher among people with very poor health (e.g. terminal conditions, those requiring frequent episodes of in-patient stays), leading to biased estimates (see above). If they do participate, responses might be partial or less detailed, interviews might be incomplete, or consent to participate in further stages might be lower, due to fatigue during the initial interview.	Fieldwork periods of at least a month, followed by a reissue stage to re-contact people not interviewed initially, increase the chance of people experiencing poor health participating (if they recover sufficiently in the extended period). Interviewers were encouraged to offer split visits if necessary, so that interviews did not have to be completed in one sitting.	Tailor questions so that some topics are missed by people with lots of health conditions to report. Or give people the option to miss topics.
Specification / Measurement error: Participants' might not report conditions that the survey question was intended to measure (e.g. hypertension is not universally reported as a long-term condition), due to misunderstanding of the requirement, or mismatch in participants' and survey designers' beliefs about conditions.	Prevalence of conditions will be under-estimated.	Cognitive testing was used to help inform changes to the long-term conditions question in 2008. This process reveals insights about participants' understanding of questions that traditional piloting methods do not (Collins 2015). Complicated or ambiguous medical terms are avoided where possible, or 'lay person' terms are used as well.	**Augment estimates with other data from within the survey (e.g. questions on specific conditions, other health problems, or prescription data from nurse interview).** Linked data can be used to identify historic hospital admissions associated with some specific conditions, but data on ongoing treatment is limited.

TSE domain and potential limitation	Potential bias	Steps to reduce bias routinely taken as part of the survey's conduct	Additional strategies that could be taken (text in bold indicates the steps explored in this thesis)
Measurement error: Potentially sensitive conditions are not disclosed (e.g. HIV, drug dependency, mental health conditions)	Prevalence of conditions will be under-estimated.	Data protection and confidentiality assurances were provided to participants in writing. Participants were told (broadly) what the survey topics would be (so could opt for a single rather than concurrent interview if they wished). Very sensitive data was collected in a self-completion.	**Augment estimates with other data from within the survey (e.g. prescription data from nurse interview).**
Measurement error: Some participants will not know that they have a diagnosed condition (e.g. if a GP has withheld information, or if they have forgotten or not understood their diagnosis).	Prevalence of conditions will be under-estimated.	None.	Some potential to use reported prescription medications to identify treated, but unknown conditions, though scope is limited by the multi-purpose nature of many drugs.

TSE domain and potential limitation	Potential bias	Steps to reduce bias routinely taken as part of the survey's conduct	Additional strategies that could be taken (text in bold indicates the steps explored in this thesis)
Measurement error: Some participants might self-diagnose conditions, or report minor conditions as more serious.	Prevalence of conditions will be over-estimated.	Long-term conditions were defined for participants, other health problems were open for participants to interpret. Doctor-diagnoses were probed for some conditions (e.g. CVD, hypertension, diabetes, COPD, asthma). Limited treatment data collected on hypertension, pregnancy-related diabetes and hypertension can be identified, impact on daily activities recorded for all long-term conditions mentioned.	Ask additional questions about circumstances, treatment and burden of conditions.
Measurement error: Interviewers record multiple conditions as single entities.	Prevalence of multiple conditions could be underestimated. Information about severity will be missed.	Instructions and training make clear that each reported condition should be recorded separately (to ensure the correct follow-up questions are asked). Coders can assign multiple codes and correct the data entry post-hoc.	CAPI could include in-built checks to remind interviewers to record information on each reported condition separately (e.g. a check could be triggered if the text entered includes "and" or "&").

TSE domain and potential limitation	Potential bias	Steps to reduce bias routinely taken as part of the survey's conduct	Additional strategies that could be taken (text in bold indicates the steps explored in this thesis)
Data processing error: Coders miscoding conditions / assigning single codes to multiple conditions.	Bias could be minimal if random and non-systematic coding errors occur (e.g. transposition of digits), but more systematic errors relating to a misunderstanding of a specific condition would bias the estimate of its prevalence.	Coders receive generic training and a tailored briefing for the project. Random checks of coders' work are performed by supervisors. The computer has in-built checks to prevent entry of invalid codes. All cases where coders are uncertain are referred to the research team for guidance. Codes for similar conditions (e.g. musculoskeletal conditions) are grouped together and reported in aggregate, so that inconsistencies in assigning codes between very similar conditions are minimised (though see Chapter 5).	Specific guidance could be provided for handling coding of multiple conditions to reduce inconsistent practices.

Data strengths

Despite the limitations and biases inherent in these (and all) survey data, there are also many notable strengths. They can be traced to two specific attributes: firstly, the kind of information that was collected in the survey, and secondly, the methodological rigour with which the data was collected and processed.

In terms of measuring multiple conditions, while this source lacks external validation (i.e. medically confirmed diagnoses), it captures people's own perceptions of their health condition burden, which can, for various reasons, differ from that contained in their medical records. SHeS is a particularly useful source in this respect as it contains a number of different measures of health conditions, rather than the just one or two questions which are typically asked in multi-topic population surveys with only limited information about health. However, the chief advantage of population health survey data is the breadth of information collected about other aspects of people's lives and experiences, which few administrative sources will ever have the capacity to record.

The survey methods described above, and the quality assurance steps discussed next, can all be said to be at the higher quality end of the population survey spectrum. For example, it uses a random probability sample, rather than a convenience or self-selected sample, which means estimates can be extrapolated to the wider population with known levels of precision (Groves et al. 2009, p.102). Face-to-face interview surveys generally gain higher response rates than postal, telephone or internet surveys, largely due to the efforts made by interviewers to contact selected sample members (Groves et al. 2009, p.150, p.153). As discussed above, this is not in itself a guarantee of less biased estimates, but direct contact methods are typically better at reaching population sub-groups who need additional encouragement to participate. Using specially trained interviewers and nurses, and standardised protocols, helps to minimise measurement error, while CAPI reduces data entry errors and allows for real-time checking of answers that interviewers have potentially mis-recorded (Groves et al. 2009, p154, p.168). The large sample enables detailed analyses to be conducted of low prevalence phenomena, or of small population sub-groups of interest.

Quality assurance processes

The quality assurance steps taken during the data collection and processing stages are documented in the technical reports for each year's survey, as referenced above, and in a data quality document (ScotCen Social Research 2009). Briefly, a high level of training and on-going supervision is provided to interviewers and nurses, selected participants are contacted afterwards to check that interviews were conducted in the proper manner, the CAPI has many in-built checks that either prevent inaccurate data entry or query potentially implausible answers, self-completion data-entry uses strict accuracy checks, coders are trained and their work is checked, and data reconciliation checks take place as the data is moved from the data preparation team to the data analysis team.

The data management conducted for this thesis was conducted in SPSS version 19 (IBM n.d.) and all stages were documented using syntax. This enabled periodic reviews of the syntax to be conducted to identify any errors. Syntax also ensures that the steps taken (both in the data management and the analysis) can replicated by third parties. Once the foundations of the definitional work were complete, the syntax to create the variables was run on a new version of the dataset so that any problems with replicating the variables could be investigated.

The various stages of the multiple conditions definition work resulted in the creation of well over 100 new derived variables, many of which were used to create the final measures reported in Chapter 5 (the syntax for which is provided in Appendix F). Errors at any point in this process would therefore have serious consequences so a multi-stage approach was used to quality assure each individual variable created for the analysis. Where possible, the syntax was adapted from existing code rather than written from scratch (this reduces some transcription errors). It was also read closely to identify inconsistencies. In most instances, errors in syntax will be flagged by SPSS and commands will not run. However, plenty of errors can still result in executable commands so further checks were run to ensure that cases had been correctly assigned. This often required numerous stages of checking, for example by running cross-tabulations with variables that were used in the derivation, or by identifying specific

sub-groups and listing their values to ensure they had been assigned to the correct categories. For example, if a variable category was intended to only include people with a specific characteristic (e.g. BMI greater than or equal to 30), a check was run to confirm that everyone with BMI ≥30 had been assigned to that category (and only that one), and that no-one with a BMI below 30 had been mis-assigned to it. This process became critical as the definition of multiple conditions became more complex.

The substantive analyses of outcomes and experiences were conducted using SPSS 19 (IBM n.d.). The SPSS analyses were similarly documented using syntax files.

Data access and ethical issues

As already noted, access to the 1998 linked data was granted by ISD Scotland, following assurances about the intended use and storage of the data, and the datafile used in the analysis was supplied via a secure server. Two versions of the combined 2008-2011 dataset were used. One was directly obtained from the survey contractors, ScotCen Social Research (see below), and supplied via a secure server. The other version was supplied by the UK Data Archive (who also supplied the 2012 and 2013 datasets[11]) (ScotCen Social Research et al. 2013; ScotCen Social Research et al. 2014; ScotCen Social Research 2014). To help inform the multiple conditions definition process, permission to access the free-text conditions data collected in the 2008-2011 surveys (but removed prior to Archiving) was sought from the Data Controllers, the Scottish Government. This is removed because reports of very rare conditions could, in combination with other items in the survey, potentially identify participants. Once approved, ScotCen Social Research supplied the data directly in a non-disclosive format – a new serial number was created that could not be linked to the main survey datasets, age was provided in 10 year bands rather than individual years, no geographic identifiers were included, and only the data items required for the task were provided (application for the special dataset is provided in Appendix C).

Ethical approval for the conduct of each of the surveys was obtained from NHS research ethics committees (REC) prior to their conduct (1998: from the RECs for all

[11] Two tables in Appendix J use data from the 2012-13 surveys.

Health Boards in Scotland; 2008 and 2009-2011: the REC for Wales, study reference numbers: 07/MRE09/55 and 08/MRE09/62, respectively).

The analysis in this thesis met the University of Edinburgh Centre for Population Health Sciences Research Ethics Subgroup's criteria for level 1 self-audit (absence of reasonably foreseeable ethical risks). See checklist in Appendix B.

Methodology

The discussion in this chapter has so far been concerned with methods, chiefly the data source used and its associated data-collection instruments. The question of the methodology adopted for this work – its ontological and epistemological foundations - has, however, been absent.

The research aims and questions set out at the beginning explicitly locate this work within epidemiology (a wholly quantitative discipline), while its concern with the social patterning of the prevalence of multiple conditions places it within its sub-discipline social epidemiology. Social epidemiology's philosophical underpinning and methods of inquiry are typically associated with the positivist tradition (Dunn 2012). Much of the existing literature on multiple conditions has little, if any, discussion of its philosophical underpinnings, or how disease/illness is conceptualised. However, the very clinically orientated field in which it has emerged most prominently as a concept (health service delivery settings and epidemiology), and the predominant use of quantitative tools to investigate it, also point to this being a field mainly associated with, or at least very heavily influenced by, positivism.

The ontological underpinning (i.e. the conceptualisation of reality) aligned with positivism follows precepts much like these outlined by Law (2004, pp.24–5, emphasis in the original):

> Out-thereness: there is a reality that is out there beyond ourselves;
>
> Independence: reality is *usually independent of our actions and especially of our perceptions*;
>
> Anteriority: reality comes before us … it precedes us;
>
> Definiteness: reality has, or is composed of, a set of *definite forms or relations*;

Singularity: the world is shared, common, the *same everywhere*.

Positivist ontology is accompanied by an epistemological position which "*asserts that the only authentic knowledge is that which is based on sense, experience and positive verification*" (Dunn 2012, p.26). Theorising about phenomena in the absence of empirical evidence does not, from this perspective, generate or constitute valid knowledge.

As Chapter 4 expands in far more detail, this thesis has sought to challenge some of these precepts, in particular, for example, around the definiteness and singularity of medical classification and illness experiences. It has done this by drawing on theoretical perspectives from medical sociology, whose ontological and epistemological foundations tend to contrast quite starkly with those from the positivist-empiricist tradition. Therefore, in adopting this approach, I have sought to inform a typically positivist empirical exercise – the quantification of a social phenomenon – with strands of thought that use non-empirical, conceptually grounded approaches, as well as those informed by empirical but not quantitative data (e.g. interviews, ethnography). A desire to place the empirical analysis within a conceptual framework, and to critically engage with that conceptualisation, has been paramount throughout. As Porpora (2015, p.21) suggests "*[w]e may successfully collect gobs of data, but if our concepts are awry, our data may be meaningless*". The following discussion outlines the foundations of this approach, while Chapter 4 contains a much more detailed discussion of its rationale and of the theoretical perspectives that have been influential.

Rubinstein et al. (2000) present two contrasting characterisations of the status and function of sociomedical categories which provide a helpful framework for situating this work. Firstly, and in alignment with the positivist principles outlined above, they suggest these categories can be thought of as providing:

> the basis for the objective classification of human health behavioral activity and experience, thus allowing us to tell what functioning falls outside of the range of normal activity. (Rubinstein et al. 2000, p.41).

And that they operate as "*natural categories whose boundaries exist, only needing to be discovered*" (Rubinstein et al. 2000, p.41).

In contrast, an alternative approach would view sociomedical categories as "*culturally and socially grounded characterizations of human health behavioral activity and experience as healthy or unhealthy, normal or not*" which are "*always the result of consensual agreement and thus are to some degree socially constructed*" (Rubinstein et al. 2000, p.41). Both approaches allow the possibility that all phenomena under investigation require some form of classification in order for them to be understood. However, they argue that whichever of these interpretations is followed determines the processes through which such identification takes place. For example, they suggest that the former position results in:

> a world view the hallmarks of which are reliance on technology for 'objective' problem assessment, an emphasis on the role of expert knowledge, and a limited acceptance of the authenticity of people's reports of their experience. (Rubinstein et al. 2000, p.42).

Whereas the latter, more socially constructivist, position permits:

> a world view that sees technology as socially situated, expert knowledge as partial and tentative, and people's reports of their experience as authentic and important for problem construction. (Rubinstein et al. 2000, p.42).

While they argue against seeing these as diametrically opposed processes, for example lay and expert knowledge are suggested to be complementary rather than conflicting sources of information, they conclude that:

> categories are reifications of processes and do not exist independently of the purposes for which they are developed. Sociomedical categories must always be treated as tentative and provisional. (Rubinstein et al. 2000, p.45).

The latter of these two positions has been influential in the approach followed in this thesis – on at least two levels – with the above caution about reification providing a particularly useful heuristic. Firstly, the identification of people with multiple conditions initially requires individual single conditions to be classified. The data source used contains both technical / objective knowledge (biomarkers, mortality records), expert knowledge (the doctor-diagnosed conditions, albeit reported through the filter of participants' accounts) and people's reports of their health problems and subjective assessments of general health status. An attempt has been made to strike an appropriate balance between these accounts to avoid privileging one set over another.

Moreover, the ontological status of disease and illness that has guided the work rejects the traditional biomedical positivist approach to these concepts and has, instead, attempted to be open to other perspectives. Nijhus and Van Der Massen (1994) characterise the ontological underpinning of modern medicine (drawing from the traditions of the natural sciences), with its mechanistic orientation, viewing humans as: "*a biophysiological and neurophysiological system … composed of an unlimited number of subsystems*" (p.2), and defining disease, consequently, as: "*disturbances in one or more subsystems, resulting in somatic, psychological, or social dysfunctions*" (p.2).

In stark contrast to the traditional biomedical model, Mol's (2002) extensive account of the nature of ontology in the medical field used an ethnographic study of atherosclerosis (a condition that results in the hardening of the arteries and, consequently, restricted blood flow in the legs), based in a Dutch hospital. Her discussion of the experience of the anthropologist Pool, undertaking research in Cameroon about the nutritional deficiency disease kwashikor, and his initial surprise at finding that people's accounts of this condition did not coincide with his Western construct of it as a fixed entity, provides a clear illustration of the problem that arises from viewing disease in this way. As she notes:

> Why would laypeople, let alone in Cameroon, delineate entities in their own talk that nicely parallel the categories of Western medicine? To presume this is to presume that the disease categories of Western medicine are "natural". That they reflect a reality out there for everyone to stumble over before interpreting it in diverse ways. (Mol 2002, pp.23–4).

Contra to such an approach, she argues that rather than being a singular entity, atherosclerosis too has multiple forms, suggesting that the atherosclerosis identified via pathological analysis differs to that revealed by sonogram investigation, or surgical intervention, or that reported by patients in the form of symptoms. Most critically, however, she argues that:

> there are different atherosclerоses in the hospital but despite the differences between them they are connected. Atherosclerosis enacted is more than one – but less than many. *The body multiple* is not fragmented. Even if it is multiple, it hangs together. (Mol 2002, p.55, emphasis in the original).

And while this kind of fragmented, non-singular, non-linear conceptualisation might feel alien at the more clinical end of medical practice, Law (2004) argues that:

> contradictions are important in the day-to-day practice of medicine. For though medical professionals usually work with a strong, perspectival version of out-thereness, this is only a means to the more important end of intervening and helping the patient. Their major preoccupation is in working out what to do. … medical professionals often have to work with multiple possible truths". (Law 2004, p.52, emphasis in the original).

Following from this, if disease is understood as something with multiple manifestations, whose discovery will be mediated by this complexity, then some of the social, cultural and historical processes that have contributed to the ways in which disease and illness have come to be understood and experienced also need to be considered, and their implications for this work illuminated. Chapter 4 does this, while Chapter 5 presents the results of bringing together these different theoretical perspectives for the purposes of identifying people with multiple conditions.

Secondly, and perhaps more fundamentally, ultimately, the analysis presented in Chapter 6 (of people's lived experiences) is an attempt to extend these lines of thinking and critically challenge and problematise the act of framing multiple conditions as a singular entity.

It is perhaps important to highlight here that, despite the approach adopted, this work remains, fundamentally, quantitative in nature. As such, there are methodological limits to the extent to which it can realise the principles laid out above. For example, the data were collected via mechanisms that are inherently reductive, losing information, nuance and context along the way. Similarly, coding and classificatory frameworks have been applied that further strip away the participants' original accounts. And while social constructivist insights have been influential, their limitations are acknowledged in Chapter 4, and my willingness to engage with ideas about the multiple constructions of disease and illness has not led me to a adopt a wholly relativist position in which these concepts are *no more than* human constructions. A belief in the "reality" of illness, and the distress and disruption it can bring for the people who experience it, and those around them, remains central to the

endeavour. However, the intention was to explore the processes involved in their discovery, to question the limits of data and the uses to which they are put, and to subject the process of quantifying phenomena to a broader set of theoretically-informed considerations than is usually the case. The overall objective was the creation of a measure of long-term conditions that was more aligned with how many people experience poor health and illness - as a constellation of multiple issues.

While the creation of population estimates of phenomena originates from the tradition of positivism, the methodology followed here arguably moves this thesis closer to the realms of post-positivist approaches, such as critical realism (see Danermark et al. 2002; Porpora 2015). However, it would be an overstatement to present this work as a fully-developed attempt at a critical realist analysis of multiple conditions, their measurement and impact. Indeed, as Porpora (2015) argues, critical realism is a philosophy of science, and as such its key function is to provoke reflection about the methods chosen to approach a research question, as opposed to providing a wholly distinct method in itself:

> No one is asking you to do what might be called CR research. What you are being asked to do is what Bourdieu asks you to do: Pay at least some attention to the philosophical grounding of your research, to what ontology you assume, what views of causality you hold, and so on. And to continually reflect on those matters in a manner that might be described as fallibalist or open to correction. (Porpora, 2015, p.208).

The core critical realist principle that, I believe, resonates in the approach I have followed is its attempt to marry the very fixed realities presupposed by positivism, and the potentially infinite realities of relativism; a process which Danermark et al. (2002) suggest is emblematic of critical realism's core properties. As Archer et al. describe it: "*critical realism claims to be able to combine and reconcile ontological realism, epistemological relativism and judgemental rationality*" (Archer et al. 1998, p.xi, cited in Danermark et al. 2002, p.10). Two additional key critical realist tenets have also influenced my approach. Firstly, its ontological position that "*the world exists independently of our knowledge of it*" (Dunn 2012, p.27) and secondly, its epistemological approach that "*all knowledge is fallible and theory laden*" which means, consequently, that "*all knowledge is subject to review, change and correction*" (Dunn 2012, p.27). Collectively, these principles

underlie my unease with wholly constructivist accounts of disease and illness which characterise these as "*mere epiphenomena of human language*" (Gorski 2013, p.662). Similarly, they have informed my critique of positions that conflate / reduce the underlying nature of disease and illness with what can be directly observed of them (Williams 1999) – committing what critical realists term the epistemic fallacy: "*the reduction of all questions of being to questions of knowledge*" (Porpora 2015, p.16).

However, as noted above, my engagement with critical realism is far from comprehensive. This work would therefore be better characterised as marking the beginning of an exploration of its potential, sparked by an interest in other people's uses of it, rather than being fully underpinned by a detailed understanding of the writings of key figures in this field such as Margaret Archer, Roy Bhaskar or Andrew Sayer. To illustrate, Pilgrim's (2013) suggestion, in relation to the problems associated with psychiatric diagnosis, that critical realism provides a framework that "*allows us to acknowledge the problem of conceptualization without reducing the whole matter under consideration to this (undoubted) problem*" (Pilgrim 2013, p.350) has been a valuable insight. This mechanism for acknowledging but not being derailed by conceptually problematic phenomena provided a helpful framework for my thinking on the meanings of disease, classification and diagnosis. Similarly, Patterson & Johnston's (2012) use of critical realism to underpin their conceptualization of obesity as a hybrid entity, simultaneously biophysical and social, provided a useful way of framing my thinking about individual conditions and the concept of multiple conditions as an entity in its own right.

Moving beyond the problems of conceptualisation, the critical realist approach to investigating and understanding the patterns typically observed in social epidemiology, and the potentially causal relationships underpinning them, that Dunn (2012) outlines was also influential in the analysis of experiences presented in Chapter 6, and in the recommendations for where this work could go next outlined in Chapter 8. Dunn describes this approach as follows:

> Traditional approaches based on positivism (e.g., epidemiology) would suggest that more data is needed, with the expectation that eventually a regularity that

> better explains the phenomenon, or one that gives more certainty to an empirical relationship, will be found. According to the realist view, however, this relationship is not self-explanatory, but must be explained with reference to what produces it. (Dunn 2012, p.29).

As reflected on in Chapter 8, these attempts to identify mechanisms that might produce the patterns in wellbeing observed represent the beginnings of my engagement with this as an approach.

The next section describes how the definition process unfolded.

Measuring multiple conditions: outline of approach taken

Introduction

The preceding sections located the work within the broad field of population health surveillance, provided specific details of the data used for the analysis, and outlined the ontological and epistemological approaches adopted. This final section outlines the steps that were taken to address the first of the research questions stated in the introduction:

- Does the Scottish Health Survey correctly identify people with multiple conditions?
    - And if not, who is missing?

As the literature review in Chapter 2 outlined, debate exists about the definition of multiple conditions, particularly surrounding the issue of what types of conditions should count and what threshold should be applied (i.e. more than one, or more than two conditions). This work has adopted the definition adopted in most of the literature based on chronic (as opposed to transient) conditions, and has applied a threshold of more than one such condition to identify multiple conditions. Other approaches, such as La Reste et al.'s (Le Reste, Nabbe, Manceau, et al. 2013), which proposed a multidimensional definition that included social and economic vulnerabilities and disease risk factors in the condition count were explored, but rejected because it does not enable variations in the lives and circumstances of people with multiple conditions to be identified once these vulnerabilities become part of the definition process. On the surface these might seem like reasonably straightforward decisions. However, operationalising these decisions in the form of a variable in the

dataset that included all people with multiple conditions required a number of stages, and drew on multiple methods and sources to inform them:

- A review of the conditions data.
- The incorporation of evidence from medical sociology literature.
- Analyses of the association between different definitions and outcomes.

The results of each of these stages are reported in Chapter 5, while Chapter 4 describes the sociological literature that informed this work in full. In reality, the separation of the process into these three stages is somewhat artificial – they overlapped and informed each other as part of an evolving and non-linear process. However, treating them as distinct stages is a helpful tool for the purpose of explaining how this work was conducted.

Reviewing the conditions data

This stage is self-explanatory; all the data recorded on conditions were assessed for their suitability for contributing to a multiple conditions measure. This involved a review of the questionnaire material as well as an in-depth analysis of the free-text data entered by interviewers. This stage used the 2008-2011 dataset, to take advantage of the large number of cases available (28,875). However, reviewing all the free-text answers to assess this would have been excessively time-consuming. Therefore, a random sub-sample of 1,000 cases with LTC free-text answers was selected from the 2008-2011 SHeS dataset using the sampling command in SPSS v19 (the main datafile was stratified by year of interview, so an even spread of years was included, and the age-sex profile of the sub-sample of cases matched that of the main dataset from which they were selected). The same approach was used to select a further 1,000 cases of OHP free-text answers. For each of the sub-samples, the text entered for the first reported condition was reviewed and coded using the code frame shown below. Answers such as "rheumatoid arthritis" were coded as a named diagnosis, while "backache" was coded as a symptom. Other codes captured scenarios that did not fall neatly into these two categories (a wider range of answers was given to the OHP questions than the LTC question, hence the longer code frame).

Table 3.5 LTC and OHP data entry codeframe

Specific named condition	1
Broad condition / body system	2
Symptom	3
Treatment	4
Injury	5
Mixture / other	6
Still under investigation (OHP only)	7
Historic / in remission (OHP only)	8

The questions addressed in this stage were:

- Were the conditions described in terms of symptoms or named conditions / illnesses?
- Did participants report obesity / weight problems as long-term conditions or as other health problems?
- How did the conditions reported as long-term and those described as "other health problems" differ?
- What was the level of agreement between the reporting of long-term conditions without prompting and the reporting of doctor-confirmed diagnoses of specific conditions?
- To what extent were conditions under-reported?
- How much granularity can the data support?

The information gathered at this stage in turn generated the following questions, which were addressed in the next two stages:

- Should the long-term conditions coding be disaggregated to enable all mentioned conditions to be counted separately?
- Should unprompted mentions of conditions such as hypertension be included in the definition?
- How should conditions reported as "other health problems" be handled?
- Should obesity be counted as a condition?
- How should under-reported mental health conditions be handled?
- Should undiagnosed conditions be included?

Incorporating insights from medical sociology

The set of questions arising from stage one were first addressed with reference to the insights that have been generated from sociological investigation of chronic illness experiences, disease classification frameworks, diagnoses and medicalisation (as

reviewed in Chapter 4). In some cases, an answer to the question was arrived at based on this literature alone, and no further analysis of outcomes was performed. In some cases, however, further analysis was warranted, as follows.

Analyses of the association between different definitions and outcomes

To complement the work carried out in the previous stages, in some cases survival analysis was also performed to see whether the inclusion or exclusion of a condition in the measure changed the association between multiple conditions and 15 year mortality rates (using the SHeS 1998-SMR linked data). To illustrate, using the example of obesity, Kaplan-Meier plots were produced to compare the outcomes of people who were defined as having multiple conditions *only* if obesity was included (i.e. they have one condition and BMI $\geq$30), with: a) people who had multiple conditions, and a BMI below 30; b) people with two or more conditions and BMI $\geq$30; c) people who had one condition and BMI <30; d) people with no conditions and BMI <30, e) people with BMI $\geq$30 and no reported conditions. Logistic regression models were then used to enable the role of potential confounders such as age and sex to be assessed. Similar analyses were conducted, this time using Cox-proportional Hazard Ratios, to compare the final definition chosen with the original one based solely on long-term conditions reported unprompted by participants.[12]

The final multiple conditions definition was therefore selected on the basis of its alignment with principles garnered from the literature, and its association with mortality.

[12] The Kaplan-Meier plots and further investigations suggested that the proportional hazards assumption was not met for some of the conditions explored, so in those cases odds ratios were estimated instead.

Chapter 4 Theoretical perspectives on measuring health conditions

Introduction

This chapter describes how the theoretical perspectives offered by sociological approaches to the conceptualisation, classification and experience of health and illness were used to inform the decisions that needed to be taken to help define and measure the presence of multiple conditions in this thesis. The approach outlined here was heavily influenced by the following observation:

> If one allows that measurement in sociology is more than a glorified labelling process, and if one grants that the labelling process itself is but a part of the way in which social meanings are generated then one can transcend arguments about the stability, arbitrariness or otherwise of our definitions and variables. (Pawson 1989, p.37)

The act of defining a concept such as multiple conditions comprises many stages, each of which has numerous associated considerations and possibilities. At the very outset, a decision needs to be made as to what is meant by condition. As the discussion in this chapter will hopefully highlight, this is less straightforward than it might at first appear and definitive positions do not necessarily exist. Obesity and hypertension provide two concrete examples of how this complexity manifests, as their status as diseases - as opposed to risk factors - is not universally agreed upon, and where measurement and threshold controversies abound. Even if agreement can be reached about what conditions are of interest, this work is presented with the challenging issue of how to handle the high volume of information that has been collected. Population-based health surveys that do not have access to clinical records on diagnoses are always faced with the question of what might be missing: how can we be sure that the questions asked have fully tapped the extent of health conditions people live with? And what about the people who did not take part in the survey? Faced with these kinds of challenges, the question arises of whether it is appropriate to use information on prescription medications or symptoms that might identify conditions that have been under or misreported. However, given what will become clear about the complex and contested nature of illness experiences, diagnosis and classification, is it appropriate to

presume that clinical records would necessarily provide a more accurate picture of people's health, or that such a thing as "an accurate picture" even exists?

In addition to the difficulties associated with defining and measuring single morbidities, the issue of what is meant by multiple is equally challenging. Some conditions can affect multiple sites, such as arthritis, which raises the question of whether such cases should be considered singular or plural, for the purposes of defining multimorbidity. Similarly, depression and anxiety very commonly co-exist, with some arguing that they are symptoms of a single underlying condition, as opposed to discrete but simultaneously experienced problems (Horwitz 2011). As will be illustrated, the very nature of the classification system adopted can mask or reveal such granularities, and the question of what level of detail is helpful or most appropriate remains, at its core, a very human one.

The above issues concern the individual decisions required to construct a measure of multiple conditions (the stages focusing on the "parts"), but considerations about the parts should not be regarded as distinct from questions about the overall purpose of the "sum". For example, the ultimate utility and validity of any measure will, in part, be linked to how it is constituted, so any decisions need to be taken while facing in two directions: looking downwards at the detail of the data and upwards at the overall purpose of the measure.

Clear parallels exist between the challenges associated with the conceptualisation and measurement of multiple conditions and those attending another, closely related, concept: disability. For example, Shakespeare and Watson (2010) caution that the huge diversity in, and high specificity of, individual disabled people's experiences could result in the single term disability "*missing the nuance through lumping a disparate group together*" (p73). Indeed, in earlier work, they argue that an overarching understanding that reflects all disabled people's experience is unobtainable (Shakespeare & Watson 2001). Their description of disability (below) raises interesting questions about the extent to which multiple conditions, as a concept, faces similar challenges in attempting to unify disparate experiences into a single entity:

> For us, disability is the quintessential post-modern concept, because it is so complex, so variable, so contingent, so situated. It sits at the intersection of biology and society and of agency and structure. Disability cannot be reduced to a single entity: it is a multiplicity, a plurality. (Shakespeare & Watson 2001, p.19).

Having outlined some of the key considerations that accompany the measurement of multiple conditions, the rest of this chapter describes the theoretical perspectives that were drawn on to inform these decisions in this thesis. A theory-informed approach was chosen, as opposed to one driven purely by the data. Before discussing the specific strands of sociological theory that were used to shape the work, the next section expands a little on what is meant by a theory-informed approach, and what value it adds.

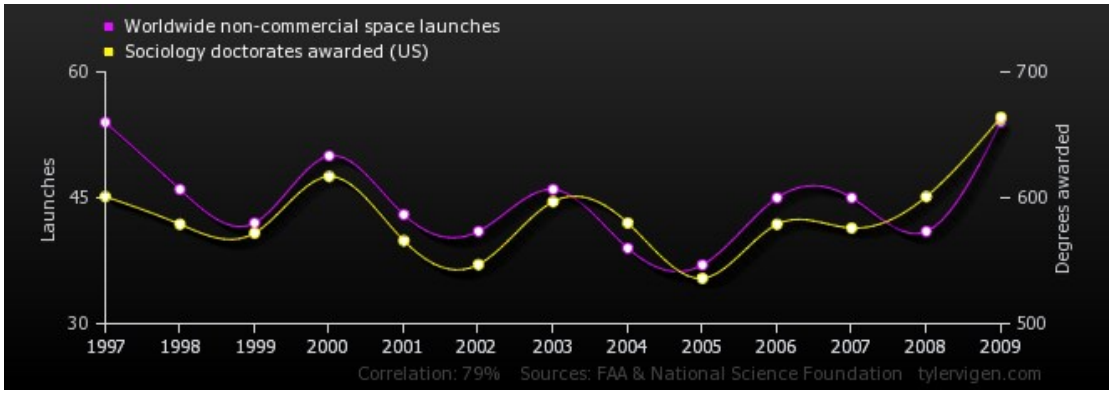
Why theory?

This approach to the analysis of empirical epidemiological data is, arguably, quite distinctive. Epidemiology, the study of population health and its determinants, has attracted criticism from within its field for being under-theorised, or even atheoretical (Dunn 2012; Krieger 2011). In contrast, medical sociology's use of theory has been characterised as uniquely distinctive, setting it apart from other health research disciplines (Cockerham 2013), though others have argued that this was not always necessarily so, especially when compared with the theoretical underpinnings and concerns of its parent discipline, sociology (Turner 1992). It is perhaps inevitable that such debates exist within and across many disciplines. In common with such debates, epidemiology has been described as genuinely underpinned by theory, but in a way that is "*seldom made explicit*" (Bhopal 2008, p.348).

Theory can be described as "*a statement that provides an explanation or coherent account of a group of ideas, facts, or observed phenomena*" (Bhopal 2008, p.3). Krieger's (2011, p.3) suggestion "*that without theory, observation is blind and explanation is impossible*" illustrates the pivotal contribution theory can make and the deficiencies its absence creates. The chart in Figure 4.1 provides a humorous but telling example of a real, observable correlation between two phenomena which, in the absence of any theoretical

framework, could be open to wild misinterpretation.[13] And while it might seem implausible that anyone would draw flawed causal links between sociology doctorates and space exploration, it is worth noting that epidemiology is a discipline whose toolbox includes explicitly atheoretical data-mining approaches such as this, designed to simply detect patterns in large datasets with no prior hypotheses (see, for example: Hanauer et al. 2013).

Figure 4.1 The correlation between worldwide non-commercial space launches and the award of sociology doctorates in the US, 1997-2009



Source: *Spurious Correlations* (http://www.tylervigen.com/view_correlation?id=805, accessed 28 April 2015).

When applied to a research problem (in any field), theory can help to formulate hypotheses about possible associations between phenomena, or mechanisms behind them, and can also serve to make explicit the principles that underline the entire methodological approach within the discipline. Within epidemiology and public health, the multiple levels at which theory is applied span the micro to the macro, encompassing ideas about how individuals enact changes in their lives to how societies function and why this contributes to specific outcomes or the emergence of patterns (such as disease distributions). Key examples of theories relating to macro-level phenomena include Link and Phelan's (1995; 2010) theory of fundamental causes (on the structural determinants of individual disease risks), Wilkinson and Pickett's (2009; 2015) spirit level hypothesis (on the association between income inequality and health

[13] The example is taken from the website "Spurious Correlations", which contains over 20,000 such examples, derived from a data mining programme written by a student at Harvard to illustrate the difference between causation and correlation.

outcomes), and Krieger's (2001) ecosocial theory of disease distribution (a multi-level approach which combines ecological, social and biological perspectives on health, across both time and place). Within public health, numerous theory-based models of health promotion and/or health behaviour change within individuals have been developed (Lewis et al. 2015 list seven).

The term "theory" can be used to describe a singular construct (a theory is…/a theory of…), but it arguably also has a status more akin to a collective noun, describing a body of work, or an overarching approach comprising multiple theories. It might therefore be more helpful to think of theory as a *framework* (rather than a statement) that *offers* (rather than provides) a means of *thinking* about (rather than explaining) phenomena. This approach acknowledges the contestable and uncertain ground that most theories occupy, as well as the possibility that multiple complementary (or contradictory) theories might be necessary to help build understanding. Furthermore, as the following argues, in the context of a discussion of the powerful influence of the French philosopher Foucault: "*we should guard against dogmatism and the myth that there can be one, all-encompassing theory to explain the complexity of modern life*" (Peterson 2012, p.17).

The above examples illustrate how theory has been applied to thinking about patterns of distributions in populations or the behaviours of individuals, rather than what theory can contribute to how a concept such as multiple conditions is conceptualised and measured. Indeed, instances of this kind of approach are rare. This is largely because surveys tend to be aligned with positivist methodologies that are predicated on an understanding of the world in which entities are largely fixed and have an existence independent of observers that, with the right tools (e.g. questions or, in the case of health surveys, physical assessments), can be measured, ultimately yielding valid and generalizable results (Moses & Knutsen 2007). Williams (2003) describes the assumption underpinning the approach to measurement in many surveys as "*there is a straightforward relationship between an object and its measurement*" (Williams 2003, para. 8.1). However, if it is accepted that illnesses and diseases are not fixed entities but instead have socially and spatially contingent properties, this clearly presents major challenges for any attempts to operationalise them for the purposes of quantification.

From some perspectives (hard constructivism, for example, as discussed below) this would represent an insurmountable barrier, with the very act of quantification considered pointless (Moses & Knutsen 2007).

Analyses of survey data need not, however, be constrained by the tenets of positivism. Instead, theorisation can be used to apply prior thought to the very nature of what is being measured and move beyond a sole focus on what can be observed (Williams 2003). The purpose of this chapter is to illustrate the ways in which I have attempted to do this, by using theoretical insights to construct a measure of multiple conditions. It is worth acknowledging from the outset that achieving a comprehensive theory-informed approach would ideally have also involved applying prior thinking to the way in which the data were collected, and what it sought to measure, rather than solely at the analysis stage. Forbes & Wainwright's (2001) critique of the use of survey data to try and understand health inequalities outlines a number of ways in which they suggest measures within official surveys such as SHeS fail to capture the complexity of the phenomena they attempt to explain. The data presented in this thesis had already been collected so the discussion of measurement implications for future surveys in Chapters 7 and 8 is an attempt to address this gap.

Why medical sociology?

This work has drawn heavily on the theoretical insights contributed by the medical sociology field, which I was drawn to via its sub-discipline of work around chronic illness experiences (Scambler & Scambler 2010).[14] I had initially sought out this literature to help fill what I felt was a gap in the "mainstream" literature on multiple conditions which, as described in Chapter 2, has been largely quantitative in its focus, with few insights into the lived experiences of people with multiple conditions (though more recent studies, such as O'Brien et al. (2014), have started to redress the balance). This exposure to sociological perspectives on chronic illness experiences led me to

[14] Debate surrounds the terms "medical sociology" and the more recently adopted "sociology of health and illness", with the former sometimes characterised as being too medically-focused and the latter as being more reflective of the broader considerations covered by the field (Timmermans & Haas 2008). However, the term medical sociology is still used widely in the field, so for brevity I have chosen to use it here.

explore other insights within this discipline, notably around the construction of health, illness and disease (Conrad & Barker 2010); classification (Bowker & Star 1999); and finally, the concept of medicalisation (Conrad 2013), which has very strong links to current debates around overdiagnosis in the more clinically-oriented medical literature, exemplified by the British Medical Journal's "Too Much Medicine" campaign (Moynihan, Heneghan, et al. 2013).

A recent review of the unique contribution that medical sociology - or, more specifically, as the review termed it, qualitative health sociology - offers, outlined seven "warrants" that could be used to underpin it as a discipline:

> examining the constructed nature of prevailing health beliefs and knowledge, witnessing health's beneficiaries and the collateral damage of a lack of health, examining the unfulfilled promises of health interventions, following financial incentives, following health across place and time, detecting causal mechanisms, and reframing dominant perspectives. (Timmermans 2013, p.6).

These warrants could equally be thought of as purposes, or roles, many of which have the potential to inform all health research, including quantitative data analysis. While some of these warrants are not directly relevant to this thesis, two particular insights that this perspective offers - that "*the current understanding of health is neither preordained nor natural*" (p2) and that *"[b]ehind the statistics lie countless individual and collective dramas that profoundly affect lives*" (p3) - helped to shape the approach followed.

It is important to note that although medical sociology undoubtedly offers valuable insights in the ways outlined above, it would be remiss to ignore some of the problems associated with its approach (while acknowledging that no approach could, of course, be uniformly flawless). Of particular relevance to this work is the charge that the preponderance of its studies have focused on single conditions - often those that could be described as "*exotic*" or "*intractable*" (Kelly & Field 1996, p.257) - from which generalisations have been made about experiences shared by *all* people with chronic illnesses (Timmermans & Haas 2008). Similarly, medical sociology's approach to the biophysical / bodily aspects of illness experiences has arguably been problematic (Williams 2006), with one view suggesting that the body has typically been characterised as having "*an ethereal quality forever gliding out of view*" (Kelly & Field

1996, p.242). The latter issue has been a particular focus of (often contentious) debate between medical sociologists and disability theorists (Thomas 2010; Shakespeare & Watson 2010). Indeed, the question of why the concept of multiple conditions - with its focus on how people experience conditions simultaneously - emerged from the more clinically-oriented fields of epidemiology, primary care and gerontology, rather than from medical sociology, which has for many decades attempted to access and reflect experiences of people living with chronic conditions, warrants further exploration and critique.

The point of highlighting the kinds of tensions illustrated above is not to diminish the contribution of the insights offered by sociological theory, but is instead intended to highlight, again, the contested nature of theory and rarity - or even absence - of definitive positions. This of course means that my attempt to use such insights to inform the kind of work pursued here involved degrees of subjectivity and experimentation that collectively resulted in a more complex and challenging approach than is typically adopted in the quantitative analysis of phenomena. However, since social epidemiology has been described as a 'bridge science', that "*combines epidemiologic principles with social science research and methods*" (Bayoumi & Guta 2012), it could be argued that attempting to inform epidemiological analysis with sociological insights is simply an extension of that bridge.

Having established the motivation and rationale for integrating sociological theory into this work, the following sections consider the specific domains that were covered. It begins with the very root of what is and can be meant by health, illness and disease.

The nature of health, illness and disease

Medical sociology arguably offers the most notable critique of, and counterpoint to, the biomedical model of disease (Nettleton 2013). The philosophical tradition of social constructivism has provided the lens through which much - though by no means all - of this critique has been framed (Olafsdottir 2013). A full consideration of the origins and tenets of social constructivism, or, more broadly, the various other philosophical approaches within medical sociology, is beyond the scope of this thesis (but can be found within Gerhardt (1989)). However, to understand how its principles

have (and have not) contributed to this work a little space must be devoted to this topic. Conrad & Barker (2010, p.s67) define social constructivism as: "*a conceptual framework that emphasizes the cultural and historical aspects of phenomena widely thought to be exclusively natural*". The critical aspect of this definition is that it highlights how social constructivism explicitly challenges existing orthodoxies, especially those that might - in some settings - be treated as incontestable. Social constructivism is a tradition whose core principles have been characterised as diametrically opposed to approaches which sit within the positivist tradition, which employ highly empirical methods, such as the population surveys common in social epidemiology (Dunn 2012). The root of this tension is not simply a question of what methodologies are deemed appropriate, but how these traditions conceptualise reality (ontology) (Bryman 2008). Constructivist approaches reject the notion of objective "truths", lying dormant until their "discovery" that are independent of human or social involvement – the position at the core of positivism. Constructivism is instead associated with views such as this:

> ...that which we take to be knowledge of the world and self finds its origins in human relationships. What we take to be true as opposed to false, objective as opposed to subjective, scientific as opposed to mythological, rational as opposed to irrational, moral as opposed to immoral, is brought into being through historically and culturally situated social processes. (Gergen & Gergen 2007, p.463).

In the context of health and illness, Lupton (2000) points out that rejecting the existence of objective or universal truths is not the same as denying the reality of the suffering that can accompany disease, rather the key issue is that: "*we can only ever know, think about, and experience these realities through our specific location in society and culture*" (Lupton 2000, p.50).

Even allowing for there to be "harder" and "softer" forms of constructivism (Blaxter 2010; Lupton 2000), with the latter being somewhat less wedded to the absolute rejection of an objective reality, it is, understandably, a perspective that many find difficult to align wholesale with the study of health and illness, where seemingly fixed and timeless disease pathologies predominate (Turner 2000), and the proponents of scientific approaches yield great power (Lupton 2000). And yet, constructivism has

profoundly influenced the way that these concepts are thought about, and constructs such as medicalisation (discussed further below) have succeeded in gaining mainstream awareness beyond the confines of medical practice or sociological enquiry (for example, Orr 2015).

The sustained challenge to the biomedical model of health, illness and disease is perhaps the clearest example of the contribution that constructivist approaches have made. They have facilitated a questioning of the notion that biological processes are the sole arbiters of what is and is not a disease (Bury 2004), and challenged an approach in which "*the body is isolated from the person … and the subjective interpretations and meanings of health and illness are deemed irrelevant*" (Nettleton 2013, p.2). The critiques offered by constructivist perspectives, typified by Freidson's (1970) pivotal work, argue that illness can have an existence that is distinct from - or even absent of - any "*biological reality*" while acknowledging that illness "*always has a foundation in social reality*" (Freidson 1970, p.212).

Much of the sociological literature on the nature and framing of health and illness highlights the ways in which these concepts have had different meanings over time, and continue to do so across social and cultural contexts, to highlight their negotiated, permeable and evolving nature (Rosenberg 1989; Blaxter 2010; Silverman & Rosenberg 2013). Kendall (1975, cited in Blaxter 2010, p.33) uses the analogy of furniture in a house to exemplify the historical development of how diseases are framed, with items from previous generations being supplemented with (rather than necessarily replaced by) new pieces, resulting in an assortment of seemingly ill-matched styles (e.g. modern plastic chairs alongside Tudor ones).

Constructivist approaches can be identified in the attempts that have been made to clarify many of the key concepts in this field. For example, Radley (1994) suggests that *disease* is the pathological disruption occurring within the body, which in turn is treated by doctors, whereas *illness* describes the way in which a person experiences disease (this distinction echoes that offered by Kleinman 1988, cited in Nettleton 2013, p.73). A third term, *sickness*, is the label that society then attaches to the person who is diseased or experiencing an illness (Radley 1994). This distinction has some

limitations, for example these terms are commonly conflated in people's everyday language (e.g. the phrases "I'm sick" and "I'm ill" are regularly interchanged). Perhaps in response to this common conflation of such labels, another descriptor - condition - is now more typically used in clinical, research and policy settings. This tends to act as an umbrella term to describe disease or illness states. For example, NHS Scotland's public information website has an A-Z listing of "conditions or treatments" (NHS Inform 2015), and the Scottish Government has a programme of work to improve outcomes for people with long-term conditions (Scottish Government 2009). This is worth noting because much of the data presented in this thesis was collected via a question that used the term "condition" (indeed, as described in Chapter 3, a conscious decision was taken to replace the terms "illness" and "infirmity" with the single term "condition" at one point in the survey series, though "illness" was reinstated at a later stage).

The idea that disease can be understood solely in terms of pathological disruptions (and partitioned from more socially-framed illness experiences) underplays the role and complexity of the processes through which underlying pathologies come to be recognised as diseases in the first place, and the fact that this complexity has, arguably, been heightened by social and technological advancements from the 20th Century onwards (Rosenberg 2002). For example, type 2 diabetes and high blood pressure have underlying pathologies that can be traced to dysfunctions at the cellular level, but the point at which they become entities that warrant treatment requires the setting of thresholds whose determination involves many factors (and potentially vested interests e.g. Moynihan, Cooke, et al. 2013) and is not simply a neutral exercise in identification and labelling. Oliver (2004, p.282) offers a useful insight on this point: "*defining impairment or disability or illness or anything else for that matter is not simply a matter of language, or science; it is also a matter of politics*".

Freidson (1970) questioned (though did not wholly reject) the practice of accepting pathologically-framed medical constructs of disease as facts, based on the seeming ubiquity of consensus around their existence, and only applying sociological enquiry to

illness experiences and their social contexts. This consensus, he argued, was only made possible via human actions:

> Consensus among humans about what physical signs and symptoms are undesirable (and therefore deviant) is high for a great number of the cases labelled "illness" - they do not seem very arbitrary. But that the consensus is high does not make it any the less a social construction. (Freidson 1970, pp.214–215).

In a similar vein, the suggestion that it is possible to distinguish between clinical entities (the signs and symptoms doctors are confronted with) and disease entities (the understandings that flow from such interactions), as proposed by King (cited in Turner 2000), also fails to resolve the question of what aspects of disease and illness can be said to be socially produced and which are not. As Turner (2000) argues, this is because clinical signs "*are mediated through and by the experiences and training of physicians, and these physicians are the products of specific and local medical cultures*" (Turner 2000, p.21).

These philosophical issues manifest themselves in the context of health and illness via the classification and diagnostic processes that are applied to some (but not all) disruptions in people's physical or mental functioning. Hence the previously mentioned variations that arise across places, time periods and social groups in how disease and illness are framed and understood are largely the consequences of variations in classification and diagnostic practices. It is these processes that have direct consequences, primarily for the people experiencing such disruptions, but also for those tasked with their treatment, and of critical importance here, to those attempting to measure their existence within a population.

The processes of classification and diagnosis

The challenges associated with defining and identifying illness and disease are replayed in attempts to classify and diagnose them. Although these are distinct acts, each of which has a particular significance for this work, they are intrinsically linked processes. Two other closely related concepts, overdiagnosis and medicalisation, are also discussed in this section.

Classification

Much of the information collected in the survey underwent some form of classification to transform the details participants reported into useable data items. Understanding more about such processes was therefore an essential part of this work. Bowker and Star (1999, p.10) distinguish between classification as an act: "*a spatial, temporal or spatio-temporal segmentation of the world*" and as a system: "*a set of boxes (metaphorical or literal) into which things can be put to then do some kind of work*". In the health field, one of the key uses of classification is epidemiological analysis, such as monitoring causes of death or illness burdens within populations (Rosenberg 2002). Indeed, William Farr, who developed the world's first national health surveillance system and whose work directly influenced the creation of the International Classification of Disease (Lilienfield 2007), suggested that disease classifications perform the function in medical statistics that weights and measures do for physical sciences (Rosenberg 2002).

More formal definitions of classification, such as that offered by ISO 17115 (cited in Madden et al. n.d., p.7), suggest that the process involves: "*an exhaustive set of mutually exclusive categories to aggregate data*". However, the extent to which any classification process can in reality be truly exhaustive, with sub-categories that are mutually exclusive, when faced with complex, socially-located information such as health states is doubtful. Bowker and Star (1999) instead describe such attributes as ideal properties, rarely (if ever) found in the classification systems humans use, and cite medicine as an example where achieving mutual exclusivity is particularly challenging (p12).

Western medical classification's origins lie in Sydenham's attempt in the late 17th Century to classify diseases using the same approach that a biologist might use to classify plants, though Krieger (2011, p.65) points out that it took another two centuries before anything like a ""*universal" nomenclature*" for diseases was achieved. The medical world is now awash with classification systems. The WHO's International Classification of Diseases, Injuries and Causes of Death (ICD) (World Health Organization 2015c) spans both physical and mental health conditions and is the oldest of the medical classificatory systems still in common use today. Initially devised

at the end of nineteenth century as a register of the causes of death, by the 1940s it had been expanded to cover non-fatal morbidity (Armstrong 2011). The first edition of the American Psychiatric Association's Diagnostic and Statistical Manual (DSM) (American Psychiatric Association 2014b) was published in the 1950s (the fifth, most recent revision was published in 2013), but the origins of psychiatric classification have a longer history dating back to the work of Emil Kraepelin in Germany in the 1880s (Shorter 2013). Although the DSM ostensibly focuses solely on mental health conditions, Rose (2013, p.124) notes that the preface to its fourth edition specifically rejected the mind/body distinction that such a notion implies and described it as "*a reductionist anachronism*". Other classificatory systems cover aspects such as functioning (WHO's International Classification of Functioning, Disability and Health), or symptoms (International Classification of Primary Care) (World Health Organization 2015d). Despite their different structures and purposes they all share the common function of attempting to assemble disparate information about health states and bring them into some sort of order. The very fact that multiple forms of such frameworks are required underlines the different manifestations of health that exist, and the contexts in which they are encountered. Another key common feature is that, like all classification systems, they are subject to negotiation, dispute and, over time, have both shaped and been shaped by, prevailing understandings of disease and illness. Armstrong (2011) describes the expansion of the ICD to cover non-fatal conditions and injuries (rather than solely causes of death), and its consequential application in hospital medicine, as a marker of "*the success of the pathological system of medicine*" (Armstrong 2011, p.802), but also highlights how ICD struggled when first confronted with the realities of how health problems are presented in primary care settings (in the form of symptoms rather than diseases).

Technology has played a major part in the shaping of health classification systems. Bowker and Star (1999) cite the example of how, historically, technology imposed constraints on the ICD's classificatory framework. The earliest version contained just 200 categories because this was the limit to how much information could be recorded on the enumeration sheets used at the time, rather than because that was how many

causes of death were thought to exist. Thus the interaction between what disease or illness states exist "out there" and human ability to capture them can be seen to be highly contingent on available resources. The expansion of technological capabilities to identify disease processes and pathologies that had previously been hidden similarly impacts on classifications, as more finely grained details of conditions are gleaned (Rosenberg 2002; Silverman & Rosenberg 2013). For example, microscopy enables sickle-cell anaemia to be distinguished from other forms of anaemia (Jutel 2011), and genomic data can be used to identify highly specific sub-types of diseases, such as cancer, heralding what has come to be known as the era of 'personalised medicine' (Savard 2013). While such advances have clear benefits when they can help target treatments more effectively, Savard (2013) highlights how focusing conceptualisations of disease and illness on the cellular level alters disease ontology by replacing illness experiences with genetic disease potential, and side-lining the role of wider societal influences on disease onset and distributions. They also valorise clinical markers as classificatory or diagnostic tools over the information provided by people reporting symptoms. The ICD-9 classification of intractable migraine provides an interesting example of this. Jutel (2011) describes the suffix "so stated" which was attached to this condition as an example of medical dominance being ceded to patients (p.8). In contrast, Bowker and Star (1999) use the same example to highlight how the term "so stated" was used to assign a potentially questionable status to patient reports, and contrast it with intractable epilepsy which was afforded no additional qualifier because it had been determined via a clinician's interpretation of laboratory information. It is worth noting that ICD-10 does not use these terms but, as Bowker and Star (1999) themselves state, the purpose of such critiques is not to condemn the terms used but to understand them in the context of how they reflect and reveal the principles encapsulated by classificatory systems when they were devised.

The extent to which conditions can be distinguished from one another is, of course, critical to any study of *multiple* conditions. If the granularity with which information has been captured is not sufficiently fine then the presence of multiplicity will not be revealed. But if too much detail has been applied then distinctions between conditions that are meaningless for the person experiencing or treating them could potentially

over-inflate estimates of multiple condition prevalence. Developing more of an understanding that classification and diagnostic practice is not an exact or fixed process, and the ways in which such systems often privilege clinical information over that provided by human report, helped me to evaluate and critique the information collected in the survey about health conditions, especially in relation to its level of detail and also in terms of what information, if any, should be privileged.

As noted above, classification is one way in which health information is organised and recorded. Diagnosis is another closely related process that requires consideration.

Diagnosis

Classification was important to consider because much of the survey data was subject to some form of it. In a similar vein, diagnosis is an important process to understand because, as will be seen, it plays such a powerful role in how people experience and ultimately report their health conditions. While Brown (1995) was the first to suggest treating the sociology of diagnosis as a distinct sub-discipline, and Jutel has arguably done the most to develop this idea (e.g. Jutel 2009; Jutel 2011; Jutel & Nettleton 2011), diagnosis has long been the subject of sociological inquiry (Blaxter 1978; Rosenberg 2002; Armstrong 2011).

In some instances, classification and diagnosis essentially perform the same function of conferring a name on a set of symptoms or behaviours deemed to be outwith an organism's normal expected functioning. This blurring of the functions of the two processes is illustrated by Jutel's (2009) initial description of diagnoses as: "*the classification tools of medicine*" (p.278). However, drawing on Blaxter, Jutel (2009) goes on to describe diagnosis as both "*a process and a label*" (p.280), with the process element relating to the act of assessing symptoms and other information, while the label is the outcome resulting from the process (so people both undergo and receive a diagnosis).

In common with the constructivist approaches to disease discussed previously, sociological examinations of diagnosis have tended to apply similar frameworks to understand it as a process, as exemplified by this observation:

> Diagnoses do capture reality, but the nature of that reality is fluid, situated, and social. Mirowsky and Ross (1989) compare diagnoses to constellations in the sky, made up of stars that are truly present but whose meaning comes from how we assemble them in recognisable patterns. (Jutel 2011, p.61)

The act of assembling recognisable patterns from underlying signs and symptoms is not a static, one-off process, but one that is often subject to re-negotiation. Such re-arrangements don't necessarily result in the diagnosis or disease label changing *per se*, but the social or treatment implications of certain diagnoses can change. For example, the constellations made up from the stars underlying MS have been re-drawn over time as understanding about its biological mechanisms has changed. It couldn't be understood (and therefore treated) as an immunological condition when it was first discovered as the concept of immune systems did not exist at the time, nor had myelin (the protective sheath encasing nerves that are damaged in MS) been discovered (Rolak 2009). Similarly, the discovery that the *Helicobactor pylori* bacterium is implicated in most cases of gastric ulcer helped alter its framing (and treatment) away from being a "lifestyle" disease (with implied personal blame due to poor diet or drinking habits) to one with a distinct pathological cause (NHS Choices 2013b).[15]

The power to diagnose lies almost exclusively with the medical profession who, as Brown (1995) describes, exercise significant powers in this respect:

> Diagnosis locates the parameters of normality and abnormality, demarcates the professional and institutional boundaries of the social control and treatment system, and authorizes medicine to label and deal with people on behalf of the society at large. (Brown 1995, p.39)

The act of giving a set of symptoms the status of a diagnosis can be shown to be a profoundly transformative process for both the person making the diagnosis and, most significantly, the person receiving it. Diagnosis can empower individuals by giving them a framework to understand their health conditions - Rosenberg (2002) talks of a "*curtain [being] pulled aside*" to reveal a "*structured narrative*" (p.255), which will, in some cases, also suggest a prognosis. Of particular importance, sociologically, is how

[15] This is not to underplay the important interaction between the bacterial pathogen and associated risks, such as poor diet and high levels of stress, which contribute to poor outcomes - the point is that this discovery has changed social and cultural perceptions of ulcers.

diagnosis can legitimise illness behaviours by locating people's experiences in the world of medicine, where a particular premium is placed on pathological as opposed to psychological roots of ill-health or poor functioning. Contested conditions, where symptoms receive the designation 'medically unexplained', exemplify this perfectly. People with such conditions often engage in significant struggles to have their symptoms recognised so they can move out of what Corbin and Straus described as "*diagnostic limbo*" (cited in Nettleton 2006, p.1168). In many instances this desire for a clear diagnosis is driven by a need for treatment – the two usually go hand-in-hand – but it is also the route through which people can avoid being labelled deviant and be given, as Nettleton's (2006, p.1167) article title suggests, "*permission to be ill*". This is an idea whose origins can be traced to Parsons' notion of the 'sick role', developed in the 1950s, in which he outlined the conditions under which people could be excused from performing the functions usually expected of adults within society (e.g. work) and, more importantly, be absolved from any blame for needing such an exemption (Nettleton 2013, p.66). However, the guarantee that a medical diagnosis will bring such absolution, or be a positive experience, is far from certain (Zola 1972). Stigma often accompanies many conditions, with wide ranging negative consequences for people's health and self-esteem, and also their outcomes across a wide range of social domains (such as housing, employment and education) (Hatzenbuehler et al. 2013). This issue is expanded on below in the section on illness experiences.

Despite the potential drawbacks noted above, for some people diagnosis clearly attaches a form of legitimacy to their experiences, hence the considerable efforts that are often made to achieve diagnostic clarity. However, medical diagnosis has also long been implicated in the labelling, control and sometimes suppression of individuals displaying behaviours deemed to be socially unacceptable, often involving debates about whether certain acts should be designated criminal, immoral or pathological (Freidson 1970; Zola 1972). One aspect of these debates focuses on the extent to which human behaviours and problems deemed socially deviant (such as alcoholism) are 'medicalized' by assigning them medical terms and applying approaches from the clinical world (such as diagnosis and treatment) (Conrad 1992). One notably outrageous historical example of the medicalisation of supposedly deviant behaviour is

drapetomania – a mental disorder that was 'diagnosed' in slaves with "*an unconscionable desire to abscond from his or her owner*" (Bynum 2000, p.1615). (The term medicalisation covers a wider territory beyond its application in the study of deviance; additional relevant examples of it are discussed further below). A more commonly cited example of disease labelling as an exercise of power is homosexuality's inclusion in the DSM - in some form until as late as 1986 (Olafsdottir 2013).[16] However, the origins of this were not necessarily intended to be malign; Conrad (2007, p.98) notes that homosexuality originally came under the ambit of medical diagnosis as a way of removing it from the more punitive jurisdiction of the penal system. Its removal from the DSM was in part due to pressure from the gay liberation movement, but also due to changes in the way psychiatric conditions were conceptualised as psychiatry underwent a shift towards a more pathologically-focused, biomedical approach (Conrad 2007; Rose & Abi-Rached 2013; Olafsdottir 2013). In many respects, homosexuality's inclusion and then removal from the DSM, and indeed, some of the recent attempts to 're-medicalise' it that Conrad (2007) describes, encapsulate much of the preceding discussion of the ways in which diagnostic and classificatory practices are highly contingent. Prevailing social norms and practices, and also changing conceptualisations of disease, each shape the nature and function of diagnoses. As Jutel (2011, p.34) suggests, the example of homosexuality illustrates: "*[that] diagnoses are* not *prior, ontological entities but* social *categories that organise, direct, explain, and sometimes control our experience of health and illness*" (emphasis in the original). Armstrong adopts a similar perspective to classification and diagnosis, suggesting that:

> Major changes in medical classification demonstrate that there are no diseases waiting in nature to be discovered; there are no diagnoses which capture an immutable illness state. Diseases and diagnoses only become apparent through the contemporary classification systems. (Armstrong 2011, p.806).

[16] Although it was removed as a blanket disorder in 1973, a new diagnostic category was added, and remained in place until 1986, for homosexual people who wanted to be heterosexual, and therefore experienced distress as a consequence.

The above characterisation of the diagnostic process could inadvertently give the impression that a one-to-one correspondence exists between the presence of a set of symptoms and their recognition by a medical professional, and that the only sociologically interesting dynamics exist within those parameters. In reality, however, the likelihood of receiving a diagnosis is itself socially contingent and various processes contribute to the situation whereby the same set of symptoms are sometimes more readily recognised in some people than others. Aronowitz (Aronowitz 2008a) used the term "framing" to describe aspects of this process, though some questioned whether he was proposing anything new, as opposed to re-stating pre-existing analyses of the socially constructed nature of disease and illness (Kunitz 2008; Nathanson 2008). However, his approach to framing was novel because it described how certain tendencies of the diagnostic process could itself contribute (albeit partially) to the social patterns in health revealed in population studies (e.g. a higher prevalence of asthma among socially disadvantaged people), as distinct from factors such as underlying biological mechanisms or differences in risk factor burdens (such as smoking). In so doing, he was attempting "*to emphasize the relevance of processes usually examined in one silo, the sociology* of *medicine, for another, sociology* in *medicine*" (Aronowitz 2008b, p.20, emphasis in the original) - an approach that has clearly been influential in this thesis. One mechanism he suggested drew on a US study that showed African Americans to have higher treatment rates for hypertension (i.e. they were more likely to be medicated) than their equally hypertensive European American counterparts (Hertz et al. 2005), though they didn't achieve better hypertension management. Aronowitz (Aronowitz 2008a) attributed the higher treatment rate to the higher than average incidence of hypertension in African Americans leading to an increased focus on this high risk group, therefore framing hypertension as a condition particularly important to treat in that population. He used a similar example, initially outlined by Gergen (1996), in which disadvantaged children (e.g. from inner cities or African American populations) with wheezing symptoms were more likely to be diagnosed with asthma than more affluent children with the same clinical presentation, despite the prevalence of symptoms showing no social patterning. This situation, Aronowitz (Aronowitz 2008a) suggested, reflected the fact that: "*Medical diagnosis is a necessarily*

Bayesian exercise. The "prior probability" of disease shapes the diagnosis" (p.3) Therefore, by taking the social distribution of a disease into account when making a diagnosis, clinicians partly contribute to that higher prevalence. Gergen (1996) suggested this meant studies of asthma prevalence needed to distinguish between "*predictors of the disease asthma, without regard to the diagnosis*" and "*predictors of the acquisition of the diagnostic label asthma*" (p.1362). These insights have clear implications for all population studies of health and illness, especially those in which social inequalities are a key focus of the analysis. This is not to suggest that such analyses should not be performed, but that the act of doing so should be accompanied, in the very least, by some reflection on the extent to which any discernible patterns could be a function of, or contribute to, this kind of framing.

A discussion of two closely-related topics now follows. Firstly, overdiagnosis, whereby diagnostic labels are attached to *risks* or *pre-disease* states, expanding and potentially blurring the boundaries of what is meant by disease (Welch et al. 2011). Secondly, medicalisation (as mentioned above), the process of assigning medical terms, or applying approaches from the medical world, to problems not previously treated as such (Conrad 2013). Some would not make such a clear distinction between the two processes, or would describe overdiagnosis as a form of medicalisation, however for the purpose of the discussion here, I feel it is useful to consider them as separate, but related topics. In both cases, specific examples of issues arising from the data that needed to be considered as part of the task of defining conditions for the multiple conditions measure will be highlighted.

Overdiagnosis and the blurring of illness boundaries

Welch et al. (2011, p.xiv) suggest overdiagnosis "*occurs when individuals are diagnosed with conditions that will never cause symptoms or death*". Moynihan et al. (2012) offer two definitions, the first of which follows Welch et al. (2011), while a second, broader definition also encompasses: "*the related problems of overmedicalisation and subsequent overtreatment, diagnosis creep, shifting thresholds, and disease mongering, all processes helping to reclassify healthy people with mild problems or at low risk as sick*" (Moynihan et al. 2012, p.e3502). In part prompted by the BMJ's 'Too Much Medicine' campaign (Moynihan,

Heneghan, et al. 2013), overdiagnosis has recently become an important heuristic for analysing and questioning diagnostic practice. Diabetes, hypertension, osteoporosis, high cholesterol, attention deficit hyperactivity disorder (ADHD), cognitive impairment, kidney disease, and thyroid, breast and prostate cancer are among the conditions typically cited in discussions of overdiagnosis – the breadth spanned arguably highlights how pervasive a phenomenon it has become, but also how widely the concept has been applied. At the individual level, concern about overdiagnosis arises from its potential to do harm - via drug side-effects, interactions with other medications, or through the stress or stigma of being labelled 'sick' (Greaves 2000; Welch et al. 2011). Overdiagnosis can also harm populations by diverting resources away from the sick towards the largely healthy (McCartney 2012), by shifting attention away from societal-level models of disease prevention (Conrad 2007), and by altering perceptions of conditions to make them seem less serious, with the consequence that the needs and experiences of people with the most severe presentations are neglected (Aronowitz 2009).

The drivers of overdiagnosis are quite diverse. A simplistic account would focus solely on the commercial interests that are served when a change to diagnostic thresholds causes more people to become candidates for pharmaceutical treatments, though this is clearly an important driver, as is the role of industry-sponsored experts on the panels that make such decisions (Moynihan, Cooke, et al. 2013). Other drivers include the growth of diagnostic technology that can identify ever more refined disease presentations (as discussed above in relation to diagnosis more broadly), a risk-averse socio-medical framework that fears underdiagnosis more than overdiagnosis, and cultural expectations that more treatment and investigations is always a good thing (Moynihan et al. 2012).

Although interest in overdiagnosis has grown in recent years, concern about the treatment of disease risk has a long history, perhaps best encapsulated by Armstrong's (1995) coining of the term 'surveillance medicine' to describe the twentieth century phenomenon of population monitoring. Originally intended as a means of managing risk and preventing illness, it has led to what he suggests is the "*the dissolution of the*

distinct clinical categories of healthy and ill" and the "*problematisation of the normal*" (Armstrong 1995, p.395). Around the same time, and in a similar vein, Meador (1994, p.440) suggested that "*well people are disappearing*". Drawing on Armstrong's (1995) work, Greaves (2000) argued that surveillance medicine has contributed to the emergence of a new type of 'partial patient':

> people who do not feel themselves to be ill or disabled either most or all of the time but who have been informed medically that because of certain personal characteristics, they have or may have a disease or other medical condition or are at risk of acquiring such a disease or medical condition. (Greaves 2000, p.23).

Among such partial patients, he suggests, are people with risks factors for disease (e.g. elevated cholesterol), asymptomatic conditions (e.g. essential hypertension), conditions in remission (e.g. cancer), and conditions that have stabilised due to treatment (e.g. diabetes or angina) (Greaves 2000, p.24). While some of these situations clearly extend beyond the narrower of the two definitions of overdiagnosis at the start of this section, and indeed the above description of the partial patient, they are all nevertheless indicative of a bigger picture in which the notion that fixed boundaries can be drawn between the sick and the well is undoubtedly redundant. This theme is also critical to Frank's (1995) concept of the 'remission society', which he links to a shift in medical practice and illness experiences from pre-modern, to modern and then post-modern models of thinking and understanding:

> In modernist thought people are well *or* sick. Sickness and wellness shift definitively as to which is foreground and which is background at any given moment. In the remission society the foreground and background of sickness and health constantly shade into each other. (Frank 1995, p.9, emphasis in the original).

These observations are important for this thesis because the measure of multiple conditions draws on information about conditions that people spontaneously report (as opposed to solely using pre-determined categories). I was therefore confronted with the challenge of how to reconcile the fact that many common conditions, such as hypertension, high cholesterol, cancer in remission and diabetes, occupy this uncertain terrain, so the extent to which people identify with them as reportable conditions varies. Consequently, I attempted in this work to develop an understanding of why

condition reporting varies that extends the explanations offered by traditional survey quality frameworks (as outlined in Chapter 3). By engaging with the kinds of themes discussed above, it has been possible to provide a more nuanced account of the challenges of measuring multiple conditions. It is not simply that our measurement tools have deficiencies (as all tools do), but also that the very concepts they are trying to capture have qualities that make the challenges of their measurement more than just a technical issue to be overcome. As Aronowitz (2009, p.419) outlines: "*Distinguishing the disease experience from the risk experience is difficult because so many developments are obliterating this difference*".

Medicalisation

Measurement challenges also arise from the consequences of the expansion of medicine into many areas of life, an overarching process described by Zola (1972) as:

> an insidious and often undramatic phenomenon accomplished by 'medicalizing' much of daily living, by making medicine and the labels 'healthy' and 'ill' *relevant* to an ever increasing part of human existence. (Zola 1972, p.487, emphasis in the original).

Obesity and mental distress are two aspects of human existence that have increasingly been framed as medical problems or diseases (Jutel 2006; Horwitz & Grob 2011). Understanding the processes that led to this situation might therefore help to guide any decisions about whether to include them in the multiple conditions measure. The following provides an overview of the concept of medicalisation, before turning to discuss these two specific examples. While much of the discussion draws heavily on Peter Conrad's (1992; 2005; 2007; 2013) work, which reflects his large contribution to this field, this is not to imply that his analysis is definitive or exhaustive. Indeed, a wider range of sources is cited in the more focused discussions of obesity and mental distress.

Much of the focus on overdiagnosis centres on diseases whose physiological manifestation involves a continuous spectrum ranging from normal to abnormal (e.g. blood sugar levels or blood pressure), with the key point of contention being where to set the threshold between these states. In contrast, while the factors typically described as being medicalised can also involve a continuous distribution and debates about

what constitutes abnormality, they also have the additional feature of being characteristics whose status as medical (as opposed to social or cultural) abnormalities can be questioned. For example, baldness, sexual dysfunction, hyperactivity, shyness and restricted height have all been subject to varying degrees of medicalisation in the form of targeted pharmaceutical treatments and, in the US at least, efforts to have their status as medical diagnoses recognised so that medical insurance will meet their treatment costs (Conrad 2007).

As overdiagnosis is one aspect of medicalisation, many of the same societal drivers of overdiagnosis outlined above are also relevant to this discussion. However, the contribution of the pharmaceutical industry has arguably been even more pervasive in this process, especially in recent decades, due to its efforts to both create and cure conditions (Conrad 2005). For example, in the case of restricted growth, Conrad (2007, p.81) cites the following statement from a doctor: "*Short stature became a disease when unlimited amounts of growth hormone became available*". Both Conrad (2007) and Horwitz (2010) devote significant critical attention to the way the pharmaceutical company GlaxoSmithKline invested heavily in campaigns to frame shyness and nervousness in social situations as a medical condition (social anxiety disorder) that could be treated by their anti-depressant Paxil (thus expanding its potential market).

As the above should illustrate, medicalisation spans a broad range of topics and has clearly been an important theoretical framework for sociologically-informed analyses of medicine. However, critics of medicalisation as a concept (as opposed to as a process) have questioned its contribution. For example, Rose (2007, p.700) described it as "*a cliché of critical social analysis*" and criticised it for implying "*passivity on the part of the medicalised*" (p. 702), especially in relation to the kinds of drug company activities just described. Bury's (1986) twin-pronged critique centred on its potential to overstate the extent to which people actually experience life as being medicalised and, more fundamentally, the social constructionist roots of medicalisation's thesis which presents difficulties linked to its philosophical positions on knowledge and what can be known. In contrast, while Davis (2006) values the contribution of the medicalisation thesis as originally framed by Zola (and others), he argued that its reach

had been extended too far (e.g. in Conrad 1992) and, by losing its original coupling with medicine, it "*encompasses too much and it stings too little*" (Davis 2006, p.56). Conrad addressed some of these criticisms, for example by making clear that, far from being passive, members of the public can be active agents in the medicalisation of issues via patients' advocacy movements (Conrad 2007). Moreover, he argues that the term medicalisation is not meant to be normative. Instead, the primary objective of its study should be the analysis of medicalisation's roots and impact, with no automatic assumptions made as to the rights and wrongs of it as a process (Conrad 2007; Conrad 2013). By way of balance, examples of benevolent medicalisation are provided, such as the transformation of epilepsy from a curse to a neurological condition with the possibility for treatment (Conrad 2013). Similarly, a distinction is made between "*unreflective*" and "*extreme*" forms of medicalisation in relation to pregnancy and childbirth (Conrad 2013, p.199), and the beneficial interventions that have reduced maternal and infant mortality and morbidity. Finally, Conrad rejects the charge that medicalisation is now too broad a concept to be meaningful, pointing out that conceptual tools need to evolve in line with social realities, with the changing role of medical professionals providing a clear example of this (Conrad 2013).

The implications of the debates outlined above for this thesis are that simply establishing that a factor being considered for inclusion in the multiple conditions measure has been described in the literature as medicalised, and therefore subjected to the critiques provided by this lens, should not be the sole deciding factor in whether it is indeed included or rejected. The task instead requires looking beyond the medicalisation label and enquiring about the associated processes and consequences that have attended the factor in question, and whether these help shape the decision about whether to include them. To an extent, the same principles apply to the issue of the overdiagnosis of risk, even though the prefix "over" carries with it a normative judgement in a way that medicalisation does not (or, at least, claims to avoid). But, whereas the insights from the overdiagnosis literature provided a framework for understanding why variations might exist in how people report their health conditions, the answer to the question of whether such risks should be excluded from the multiple conditions measure requires additional insights. In contrast, the primary

consideration in relation to medicalised factors is whether they should be counted as conditions that contribute to the multiple conditions measure. Two key examples of factors that posed this challenge are outlined below: obesity and symptoms of mental distress.

Illness experiences

Strauss and Glaser's 1975 work *Chronic illness and the Quality of Life* is widely acknowledged as the first sociological investigation of the lived experiences of people with long-term illness to recognise the importance of subjective accounts to understand the impact of illness (Conrad & Bury 1997; Charmaz 2010). While Parsons' work on the sick role arguably established the first framework for understanding illness as a socially and culturally-mediated process, Strauss and Glaser's work laid the foundations of a less medically-dominated approach and therefore helped to uncover the kinds of struggles and adjustments that people who live with illness on a permanent basis face in their daily lives (Conrad & Bury 1997). Subsequent to this, the 1980s onwards saw a huge growth in the study and understanding of long-term illness experiences, resulting in numerous, broadly complementary rather than conflicting, perspectives. For example, the impact of long-term illness on people's identity and sense of self is an important aspect of Bury's concept of illness as biographical disruption, Charmaz's work on the loss of self associated with long-term illness onset, and Williams' (somewhat more positive) idea of narrative reconstruction and the way in which people make sense of their experiences following diagnosis (Lawton 2003). The longevity of this identity-oriented perspective is underlined by the fact that concepts such as biographical disruption still feature prominently in the research literature on long-term illness experiences today (see, for example, Bray et al. 2014). Corbin & Strauss's (1985) article on the work associated with living with chronic illness – and in particular their emphasis on how this interacts with the work associated with people's everyday lives - has been similarly influential.

As discussed earlier, this body of work has attracted various criticisms (which don't need to be repeated here), but a specific omission of relevance to this thesis, which has

not been raised in any literature I have found, is the fact that the predominance of studies based on single specific conditions leaves many questions unanswered about the illness experiences of people with *multiple* conditions (especially those experienced sequentially, rather than diagnosed simultaneously). For example, are biographical disruption and loss of self phenomena that people experience anew with each additional diagnosis, in a loop-like fashion? Or are new conditions less disruptive, less damaging to the self, for people who have already experienced one round of narrative reconstruction as a consequence of a long-term condition diagnosis? These questions have not been directly addressed in the sociological literature to date, but a number of qualitative studies looking at people's experiences of living with multiple conditions have started to explore some aspects. For example, Hurd Clarke & Bennett (2013) explored the gendered experience of multiple conditions in older age and highlighted how both men and women accommodated and framed their illness experiences as inevitable consequences of ageing, which they describe as a form of 'biographical flow' as opposed to the biographical disruption as conceived by Bury. O'Brien et al. (2014) explored the illness and everyday life work associated with living with multiple conditions among people of working age, highlighting the considerable struggles people face, especially when deprivation and mental health problems were among the challenges they faced.

In terms of people's capacity to adjust to multiple conditions, Sells et al. (2009, p.99) suggest that Knudson's (1971) "two-hit" theory, which sets out a mechanism whereby two independent factors collide and cause a negative health outcome (such as cancer) that would not have occurred had just one of the two factors been in place, might usefully be applied in this context. For example, they argue that the period of adjustment and reconciliation following the onset of a single disease can be experienced almost like a wake, featuring "*a period of necessary grieving, entailing reflection and the testing of modified routines, roles and identities*" (Sells et al. 2009, p.99) during which time the addition of further conditions:

> may conspire to flood time and attention with seemingly continual patient-related concerns, engulfing any space of mindfulness one might use towards constructing more gainful identities. (Sells et al. 2009, p.99).

In contrast, Liddy et al. (2014) suggest that:

> repeated poor health and increasing suffering create a tipping point for patients, whereby they are able to take charge of their health more effectively, despite having multiple chronic conditions. (Liddy et al. 2014, p.1130).

The nature of the work presented in this thesis cannot resolve such questions, but it is important to acknowledge the gaps in these theoretical approaches as well as to identify where they provide useful contributions. I believe they are still useful, despite such limitations, because they nevertheless highlight the extent to which living with long-term ill-health represents, for many, a serious encroachment on people's lives, as Frank (1995, p.56) describes it: "*[d]isease disrupts a life, and illness then means living with perpetual interruption*". As a consequence, there is an argument that health analysts have a duty to ensure that the data that have been collected reflect, as far as is possible, the full extent of these experiences. But also, in conjunction with insights above about the fluid nature of disease classification and medicalisation of risk, the fact that illness experiences can have such a profound impact on people's lives means that any perceived "failures" to report health conditions need to be given some thought before being dismissed as participant errors. How people perceive health conditions and contextualise them in their lives will clearly shape how they answer survey questions. Lawton et al.'s (2005) study of people's experience of type 2 diabetes illustrated this perfectly – those with no discernible symptoms (following treatment) often questioned their diagnosis, and clearly experienced their illness very differently to those for whom a health condition continues to involve significant symptoms following their diagnosis. Similarly, Duguay et al.'s (2014) participants drew clear distinctions between conditions with a direct bodily impact (e.g. pain) and those with no physical manifestations; as one interviewee (with nine conditions) stated: "*Day-to-day my life is normal. The only time I think about having diseases is when I've just met with the doctors*" (Duguay et al. 2014, p 15). Increasingly, however, these kinds of symptomless conditions (high blood pressure and high cholesterol could equally be included here) now bring with them treatment and monitoring regimes that can themselves bring about the kinds of shift in identity that are more typically associated with physically embodied illness experiences (hence some of the concerns noted above about

medicalisation and the creation of partial patients (Greaves 2000)). Furthermore, following from the discussion above of the significance of receiving a diagnosis, it is also the case that a diagnostic label in the absence of any symptoms can be harmful, as Scambler & Scambler (2010, p.3) suggest with reference to misdiagnosis: "*a considerable psychosocial price can be paid in the absence of any underlying (psycho-)pathology: a label can in and of itself prove decisive for quality of life*". However, the following observation from one of Lawton et al.'s (2005) study participants, also provides a useful illustration of the extent to which illness experiences can be mediated by people's wider beliefs about health, their confidence or trust in medical "authority", and their direct experience of physical symptoms:

> I just wonder how many other people are like me cos they seem to go through five year- I call it the five year cycle. It was the cholesterol for five years, then it was the high blood pressure for five years and now it's the diabetes, y' know. So what's going to be the next thing, y'know? (participant quote, cited in Lawton et al. 2005, p.1428).

As the discussion of medicalisation and overdiagnosis above highlighted, the answer to this arguably prescient question could be any number of things, for example dementia (NHS England now incentivises GPs to identify cases (McCartney 2014)), or perhaps pre-diabetes (NICE is currently consulting on plans to identify people at risk of diabetes in England, despite concerns about its measurement (Yudkin & Montori 2014)).

Illness experiences are, therefore, clearly quite diverse, and can be profoundly disruptive of people's routines and also their sense of self, and bring considerable work. However, potential clearly exists for people to frame their experiences with reference to both physically embodied symptoms and wider social and cultural expectations and responses to ill-health, a process Radley (1994) describes as adjustment. However, the extent to which the diagnostic distinctions drawn by medical nosology map onto people's lived experiences of distinct conditions is also unclear, especially if multiple conditions yield similar functional impairments which "*blend into one*" (Ong et al. 2014, p.313).

Additional challenges arise when people have conditions associated with social stigma. Scambler (2009, p.441) defines stigma as:

> [..] typically a social process, experienced or anticipated, characterized by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgement about a person or group.

In the health context, stigma is especially associated with conditions linked to sexual behaviour (in particular HIV), neurological conditions (epilepsy has been the subject of much work around stigma), and mental illness (Pierret 2003; Corrigan et al. 2005; Pescosolido et al. 2008; Scambler 2009). Stigma operates in multiple forms, as the above quote reflects, with a particularly important feature being the way that it can be harmful not only as a result of the direct experience of stigmatising behaviours and attitudes, but also due to the anticipated fear of such responses (this aspect was first described by Scambler & Hopkins (1986) as "enacted" and "felt" stigma). Consequently, the stigmatisation of certain health conditions creates particular challenges for population studies based on self-reported information, due to people's reluctance to disclose the existence of such conditions, partly fuelled by fear of a third party's response, with the concealment of mental health conditions particularly common (Corrigan et al. 2013). Citing work by Link and Phelan, Scambler (2009) notes that stigma is not solely about the way that individuals treat each other, but that "*stigma is entirely dependent on social, economic, and political power – it takes power to stigmatise*" (Link and Phelan 2001, cited in Scambler 2009, p.450). Following this, stigma has also been conceptualised as a "*central driver of morbidity and mortality at a population level*" (Hatzenbuehler et al. 2013, p.e1). Others argue that neoliberalism actively requires the stigmatisation and shaming of socially marginalised people with poor health in order to underpin its tenets and reinforce its continued hegemony (Peacock et al. 2014; Bissell & Peacock 2015). The study of health and illness therefore also has an additional responsibility to ensure that it is not conducted in a manner that stigmatises, or reinforces the existing stigmatisation of, groups of people on the basis of their conditions or other health characteristics. This especially applies to studies that have some official status, such as those that generate population estimates

for public bodies (such as the data used in this thesis). Examples of how this could happen include the adoption of unnecessarily risk-averse approaches that exclude people with HIV or other blood-borne viruses from biological measurements (or mandating the use of surgical gloves in such cases, rather than for all participants). Health studies can also contribute to indirect stigmatisation via the way that issues such as obesity or alcohol and other substance misuse disorders are described and framed in subsequent analysis and reporting. For example, using pejorative rather than neutral language, or graphics that compound stigmatising attitudes, or failing to acknowledge that critical debate surrounds such constructs and instead presenting certain aspects as uncontested facts. The case study of obesity presented below in particular illustrates how its framing as a disease (and its measurement and classification) exemplifies these points.

Case studies: obesity and psychological distress

Introduction

The perspectives and insights on health, illness and its classification and impact on people's lived experiences discussed in this chapter were not intended to simply provide some theoretical context to an otherwise wholly quantitative empirical analysis of the prevalence of multiple conditions in the adult population in Scotland. Instead, the point was to provide a framework for approaching the analysis in a more nuanced way, drawing on such insights to shape and, hopefully, enable the thesis to be more grounded in the experiences of people living with multiple conditions. The next chapter provides a fuller overview of how this has worked in practice for a series of decisions about how the data were handled. However, the topics of obesity and mental health problems and disorders stand out as having been particularly shaped by this approach. They are therefore considered in more detail here.

Obesity

Obesity is typically defined as excess body weight as a consequence of accumulating fat (Tremblay & Doucet 2000). The WHO's definition also includes a quantification of this excess - a body mass index (BMI), derived from height and weight, of 30 or more[17] - and a reference to its consequences for health (World Health Organization 2015a). The measurement and classification of obesity is a controversial and complex topic and its standard metrics (BMI and waist circumference) and thresholds have all been the subject of criticism (Nicholls 2013). Nevertheless, obesity (BMI $\geq$30) has become an important public health issue and is the subject of clinical guidelines, population initiatives to reduce its prevalence (Foresight 2008; SIGN 2010; Scottish Government 2010), and wildly varying estimates of its financial burden to health services and the wider economy - Castle (2015) cites a figure of £0.9 to £4.6 billion per year in Scotland.

[17] BMI = height (cm) / weight squared (kg^2). A BMI of below 18.5 is considered underweight; 18-5 to <25 normal weight; 25 to <30 overweight; 30 and over obese. Further distinctions are often made within the upper range to identify a more severe form of obesity of BMI 40 or more.

Obesity serves as an exemplar of many of the themes discussed above in relation to disease framing, classification, medicalisation and illness experiences. However, the most prominent issue of contention is arguably the extensive debate about its status as a disease, as opposed to a risk factor for poor health or marker of other pathologies (Tremblay & Doucet 2000; Heshka & Allison 2001; Kopelman & Finer 2001; Jutel 2006; Allison et al. 2008; Chaput et al. 2012; Hurt et al. 2014). The impetus to designate it a disease was arguably a matter of pragmatism, linked to the US-based health insurance model that requires the treatments it funds to be associated with specific diseases – coupled with the rise of drug and surgical interventions for obesity - rather than the result of a scientific process to adjudicate its status (Chaput et al. 2012). Though, as Chaput et al. (2012) acknowledge, and the preceding discussion in this chapter should have made clear, disease designation is always a multi-faceted, and ultimately human, process that doesn't necessarily follow strict criteria, so the contested nature of its disease status should not be surprising. However, while unsurprising, the latest of The Lancet's series on obesity also highlights how the question of its designation as a disease is just one of a much wider set of controversies surrounding the topic, which they characterise as:

> false and unhelpful dichotomies: individual blame versus an obesogenic society; obesity as a disease versus sequelae of unrestrained gluttony; obesity as a disability versus the new normal; lack of physical activity as a cause versus overconsumption of unhealthy food and beverages; prevention versus treatment; overnutrition versus undernutrition. (Kleinert & Horton 2015, p.2326).

Whether or not to consider obesity a disease is clearly a key consideration in whether it should be included as a condition in the definition of multiple conditions, while measurement issues form the basis of secondary considerations about *how* to include it. Both of these issues, in part, explain why obesity is largely absent from the conditions reported in most of the published literature on multiple conditions. Five of the 39 multiple conditions measures reviewed by Diederichs et al. (2011) included obesity, though it is unclear whether its inclusion / exclusion from the measures was due to data availability (many administrative data sources lack robust or complete

measures of height and weight) or active choices about whether to include it (the review does not discuss this). Related to this, the publications library maintained by the International Research Community on Multimorbidity (2015) does not include any articles addressing this issue specifically, and where obesity is explicitly mentioned in an article title its focus tends to be on obesity as a risk factor for chronic conditions (not as a condition in itself). The question of obesity's exclusion from Barnett et al.'s (2012) study of multiple conditions in Scotland was discussed in post-publication correspondence (Wang et al. 2012; Guthrie, Watt, et al. 2012). The original authors justified its exclusion by highlighting the relative scarcity of previous studies including obesity as a condition, and (most critically) the lack of obesity data in their study source, without making a definitive suggestion about whether it should, ideally, be included (though severe obesity was flagged as potentially having a similar status to uncomplicated hypertension) (Guthrie, Watt, et al. 2012). Similarly, the pre-publication review comments on a study of obesity and chronic disease clustering largely centred on the issue of whether the estimates of multiple condition prevalence (and subsequent analysis) presented should include obesity in their definition (Agborsangaya et al. 2013a; Agborsangaya et al. 2013b). The authors justified doing so on the basis that the American Medical Association has, since 2013, defined it as a condition, but this discussion is confined to the pre-publication correspondence with reviewers. The main article itself is weak in this respect, simply stating that "*Its inclusion in studies on multimorbidity is thought to be vital*" (Agborsangaya et al. 2013a, para 2) with no evidence presented beyond the post-publication correspondence on Barnett et al. (2012) cited above (Wang et al. 2012; Guthrie, Watt, et al. 2012).

Its disease status in clinical and research circles should not, however, be the sole consideration. The lived experience of people with a BMI in the obese range also matters – if such people do not identify their weight as a health condition or disease then using their physical measurements to assign them a disease label arguably demotes their agency in the process. As this thesis is attempting to reflect, as far as is possible with the kind of data collected, the conditions that people live with, then the question of whether people need to actively identify with their condition status for it to be included is an issue to consider. However, another important aspect of the lived

experience of multiple conditions is how they impact on key outcomes, such as quality of life and, ultimately, mortality. If an additional negative association can be demonstrated between the existence of multiple conditions and lifespan when obesity is included as a condition, then arguably there are more grounds for its inclusion.

In addition to the above points, the factors that make obesity's disease designation and status as a public health issue of concern controversial, such as debates about the extent to which it genuinely represents a risk to health (Campos et al. 2006b; Kim & Popkin 2006; Orbach 2006; Blair & LaMonte 2006; Flegal 2006; Lobstein 2006; Stevens et al. 2006; Rigby 2006; Campos et al. 2006a; Gard 2011a), and the social, political and personal consequences of its framing as either a disease or a health risk (Gard 2011b; Patterson & Johnston 2012; Saguy 2013; Guthman 2013) also make the question of its inclusion in multiple conditions analyses similarly fraught. From a population health perspective, one of the problems with classifying obesity as a disease is the danger that this frames it as a medical problem *within* individuals, requiring clinical interventions such as bariatric surgery, drugs to aid weight loss and targeted weight-loss interventions (Saguy 2013), rather than as a problem *of* societies, requiring action to address the problematic social, political, economic and environmental circumstances that collectively contribute to weight gain in individuals (Moodie et al. 2013; Schrecker & Bambra 2015).

Whether it is included or excluded, the decision cannot (or, at least, should not) be separated from these wider debates surrounding obesity, nor those discussed in previous sections in relation to the medicalising of risk and overdiagnosis. Having considered these issues, it is clear that including obesity has the potential to reify its status as a disease and health risk (even if done tacitly), especially as other studies often look to previous practice to help frame definitional decisions. In contrast, excluding it could be framed as an explicit rejection of its disease status and associated health risk which, depending on the justification given, could be aligned with the arguments of those who question the existence of negative health consequences resulting from obesity, for example the Health at Every Size and Fat Acceptance movements discussed in Saguy (2013).

Mental health problems and disorders

The themes discussed in this chapter have particular resonance in the context of problems and disorders that affect psychological functioning, such as thought processes and emotions, as distinct from those with only a physiological element. The former of these is often grouped under the umbrella term *mental health*, in juxtaposition to *physical health,* though the notion that such a binary distinction exists between these concepts is generally considered unhelpful (Rogers & Pilgrim 2005). The debates surrounding the nature and construction of disease are amplified in this domain, with the dividing line between being mentally well and mentally ill a much contested territory, not just historically but still also today (Leader 2011; Pietikainen 2015). As with the discussion of obesity, the point of what follows is not to adjudicate on this and other controversies in this field. Rather, the point is to highlight the existence of such debates and draw out their implications for the study of ill-health in populations. The implications are somewhat wider ranging than was the case with obesity, hence the additional space devoted to this topic in the discussion that follows.

Terminology is rarely neutral. For the purpose of this discussion, and for reasons that will hopefully become clear, I have chosen to use the term *mental health problems* to cover the broad range of psychological symptoms that can have a negative impact on people and which all people encounter at some point in their lives, and *disorders* to indicate a subset of those symptoms or collections of symptoms that represent rarer and more severe levels of dysfunction.

Mental health problems and disorders occupy a pivotal position in debates about the social construction of health and illness (Rogers & Pilgrim 2005). This is largely (though not solely) because of the ongoing failure to definitively identify organic underpinnings for most disorders, despite many efforts to do so within the structure of the brain, its neurochemistry or, increasingly, within DNA (Rose & Abi-Rached 2013). Commenting on this failure, Paris (2013, pp.40–41) suggests: "*[w]e are no closer to understanding the etiology and pathogenesis of mental disorders than 50 years ago*". The following observation reflects how this situation has shaped some people's approach to mental disorders and their ontological status:

> Biological psychiatry has failed to produce quick, convincing explanations for any of the mental disorders. This is because it has been unable to circumvent the fundamental and inherent flaw in the biological, "realist" approach—mental disorders don't really live "out there" waiting to be explained. They are constructs we have made up—and often not very compelling ones at that. (Frances 2013, p.96).

As a consequence, the identification of mental health problems is dependent on descriptions of symptoms which, as Pilgrim (2013) describes, brings problems because "*they are negotiated intersubjectively in a culturally context-bound, and thus fluid or open-textured, manner*" (Pilgrim 2013, p.337). It is important to highlight that approaches such as those articulated in the preceding quotes do not necessarily deny the existence of mental disorders in humans, and the reality of the significant burdens and distress they can impose. Rather, their intention is to problematize their framing, origins and application. They are therefore quite distinct from perspectives that reject the notion of mental illness outright, such as the prominent anti-psychiatry figure Thomas Szasz's view that mental illness was a "*scientifically worthless and socially harmful*" concept (Szasz, 1974, cited in Pietikainen 2015, p.312). Although the critiques that had sympathy with this kind of view no longer have the influence they perhaps did in the 1960s and 1970s, their contributions unquestionably helped shape the understandings of mental illness and forms of psychiatric practice that exist today (Horwitz 2011; Pietikainen 2015). Though perhaps not in ways that they might have intended. Many cite the groundswell of criticisms of psychiatric practice in the 1970s (from academic circles and wider popular culture) as a driver of the concerted efforts that followed to develop a more bio-medically focussed model of psychiatry with an overt emphasis on reliable (i.e. replicable across time and context) classifications for conditions (Horwitz 2011; Kinghorn 2013). The outcome was the DSM-III, published in 1980, which radically moved the classification of mental disorders away from the previously dominant psychodynamic approaches (heavily influenced by Freud) towards symptom-oriented, purportedly more robust, diagnostic criteria (Shorter 2013). However, some argued that there was a danger inherent in this approach, namely a failure to address the question of validity:

> The focus on reliability provided the justification for psychiatry to claim it was scientific without having to demonstrate why any of the classified entities ought to be considered instances of mental disorder. (Horwitz 2002, p.69).

Another criticism of the DSM approach, from DSM-III onwards, has been its failure to demonstrate that its classified entities were genuinely distinct from one another, as opposed to being symptomatic of broader conditions or dysfunctions. For example, Horwitz argues that:

> ...most nonpsychotic symptoms stem from general underlying vulnerabilities that may assume many different overt forms, depending on the cultural context in which they arise. Particular symptoms do not indicate underlying diseases; they are symbols that have a more arbitrary connection to what they represent. (Horwitz 2002, p.108).

The DSM is therefore emblematic of the wider challenges associated with the development of classification frameworks discussed above. But those challenges are heightened by the lack of consensus about what constitutes mental disorder. Consequently, the ability to meaningfully delineate its various manifestations is similarly problematic. As Frances (2013, p.102) suggests: "*Our classification of mental disorders will always necessarily be no more than a collection of fallible and limited constructs that seek but never find an elusive truth*". Similarly, Kinghorn argues:

> The DSM would appear to be an artifact of *bricolage*, a catalogue of conditions in which psychiatry happens to take some interest and which have historically been constructed as proper domains of psychiatry's authority (Kinghorn 2013, p.59, emphasis in the original).

At the crux of perhaps the most sustained critique of the post DSM-III approach to classification and diagnosis was its supposed lack of contextual grounding, as Horwitz and Wakefield have argued in relation to anxiety: "*...pathology cannot be equated with the sheer presence of negative emotions, since bad feelings can often exist for good reasons and be normal*" (Horwitz & Wakefield 2012, p.33). This failure to adequately address context, Horwitz and Wakefield argue, has been exploited by others and contributed to an increase in diagnoses; a process that has attracted the interest of analysts of medicalisation and overdiagnosis. At the heart of this problem, it is argued, is a failure to fully appreciate what is normal, in order to better understand and identify what is not (Horwitz & Wakefield 2012). Though it is worth highlighting that this critique

largely centres on the status of disorders with non-psychotic symptoms, such as depression and anxiety, where severe and dysfunctional sadness and fear exist at one end of a continuum that also includes less severe, arguably "normal" manifestations of these same emotions. Horwitz's position is therefore based on the premise that psychotic symptoms, such as auditory and visual hallucinations or delusional thoughts, have a much less ambiguous status, though this partitioning is itself potentially contestable (Rogers & Pilgrim 2005).

Conrad (2007) implicates pharmaceutical industry interests and activity in the rise in diagnoses of conditions such as social anxiety disorder, whereas, Horwitz (2011) argues that the association between such vested interests and the widespread growth of these types of conditions has been mediated by classificatory elasticity:

> ...the DSM-III diagnostic criteria transformed a condition that was thought to be very serious and rare into one that was extremely common. A number of interest groups capitalized on this aspect of the MDD [major depressive disorder] diagnosis and shaped it to their own ends. (Horwitz 2011, p.42).

In this context, therefore, a symbiotic relationship could be said to exist between the nature of the approach used to diagnose many mental disorders, and the potential this then opens up for various parties to exploit this feature for commercial or other forms of gain (e.g. the receipt of research funds, professional prestige) – and to further introduce new diagnostic labels, thus beginning the loop again.

The DSM's most recent, and certainly most controversial revision (Paris & Phillips 2013), resulted in the release of DSM-5 in 2013 (American Psychiatric Association 2014a). DSM-5 arguably now has the status of being the medical classification tool most widely known about beyond the confines of its own domain (see, for example: NHS Choices 2013a), following very public disagreements within the world of psychiatry. Perhaps the most notable criticism has been from Allen Frances - one of the architects of DSM-IV - who described DSM-5's approval as "*the saddest moment in my 45 year career of studying, practicing, and teaching psychiatry*" (Frances 2012, para. 1), chiefly due to his concern that its further loosening of diagnostic criteria would lead to "*diagnostic hyperinflation*" (Frances 2012, para. 22). Such hyperinflation, he argues, diverts attention and resources away from very seriously ill people towards people "*with*

the everyday problems of life" (Frances 2012, para. 22), echoing the concerns outlined by Aronowitz (2009) in relation to the merging of risk and disease boundaries.

But why do the above issues pose a challenge for the study of population health, and in particular, multiple conditions? A number of issues arise, chief of which is the fact that two simultaneous processes conspire to make the estimates of mental health disorders in population surveys quite problematic. Firstly, as noted in the main discussion, the stigma associated with these kinds of conditions can lead to under-reporting of diagnoses to survey interviewers. Secondly, while much of the above discussion focused on the danger of medicalisation and overdiagnosis, underdiagnosis also occurs (Pierre 2013). So it would be possible for someone to be living with severe and impairing mental health problems in the absence of any "official" diagnosed disorder, which if detected by the survey might potentially warrant inclusion as a condition if the aim is to reflect as far as possible the true extent of people's lived experience of illness – named or otherwise. Any study of multiple conditions is further challenged by the issue of where to set boundaries round diagnoses or symptoms; for example, should someone reporting a diagnosis of, or reporting symptoms of, depression *and* anxiety be counted as having two sets of problems, or just one?

The critical challenges are therefore three-fold: how to address the issue of under-reported psychological disorders, how to make a meaningful distinction between symptoms that reflect general problems and more severe disorders, and how to handle reported diagnoses of multiple disorders. Many general health surveys, SHeS included, include measures of psychological distress and / or mental wellbeing. In addition, studies with a specific focus on mental health symptoms and diagnoses also exist, such as the Adult Psychiatric Morbidity Survey in England (Mental Health Surveys 2012) and the National Comorbidity Survey in the USA (National Comorbidity Survey 2005). While the aims and topic coverage of these studies may vary, they tend to share common methods, such as the use of validated measurement tools. The tools used in SHeS were intended to identify potential symptoms of non-psychotic psychiatric disorders and positive mental wellbeing. They were the:

- 12-item self-completion General Health Questionnaire (GHQ-12) (Goldberg & Williams 1988);
- 14-item self-completion Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS) (Tennant et al. 2007); and
- a sub-set of items from the Revised Clinical Interview Schedule (CIS-R) (Lewis et al. 1992) to measure anxiety and depression symptoms, self-harm and suicide attempts for the sub-sample of adults interviewed by a nurse.[18]

As discussed above, the most sustained criticisms levelled at survey measures of mental distress *symptoms* surround the question of whether they can, in themselves, be treated as proxies for psychiatric *illnesses* (Horwitz 2002; Horwitz 2010; Horwitz & Grob 2011). Hence, when GHQ-12 results are presented, they are usually described as indicating "*possible psychiatric morbidity*" (Wilson et al. 2015, p.6). In clinical settings, diagnostic psychiatry is meant to draw on information about symptoms as well as their context, duration and impact (Horwitz & Grob 2011). The chief concern is that while population surveys cover symptoms, they rarely measure duration or impact (other than superficially), and in the case of the various measures included in SHeS, have no details about context. A person reporting symptoms of sleeplessness, sadness or anxiety due to a recent bereavement, or a stressful event such as an exam, job interview or relationship breakdown, might not, therefore, be distinguishable from someone with the same symptoms as a result of a serious disorder. The fact that such symptoms are reported with the caveats noted above about only reflecting *possible* conditions can easily be lost in subsequent citations.

The use of surveys to identify psychiatric disorders is therefore highly problematic. The roots of this lie not only in the survey process itself, but in the wider difficulties associated with the contested ontological reality of mental health problems and disorders, and their labelling and diagnosis. However, simply disregarding the information that people have volunteered about their diagnoses and symptoms of

[18] From 2012 onwards these questions moved to a computer-aided self-completion section of the interview and were asked as part of the biological module conducted by specially trained interviewers that replaced the nurse visit.

distress on these grounds would deny the reality of distressful and often disabling experiences. Instead, it is suggested that a critical realist approach can resolve this as it: "*allows us to acknowledge the problem of conceptualization without reducing the whole matter under consideration to this (undoubted) problem*" (Pilgrim 2013, p.350). Pilgrim goes on to argue that while the diagnostic labels of schizophrenia, personality disorder, major depression and anxiety disorder *themselves* might not add insights to the problems they describe, the underlying reality of what they describe remains, and that is what should draw our attention:

> whatever we opt to call variable experiential states of misery, many people really are miserable in many contexts. And so, tentatively, we might begin to trace the reasons why people are miserable at some times in their lives and not others. (Pilgrim 2013, p.351).

Implications for this work

The various main strands of theoretical insights outlined above have influenced the analysis conducted in this thesis in a number of ways. Specific examples are provided in the next chapter, however the overarching principles that they generated can be summarised as follows. Quantitative analysis should:

- explicitly acknowledge the limits of quantification and be clear that measuring and classification do not, in themselves, reify phenomena;
- understand that complex human experiences, such as illness, cannot be neatly captured by single measures, and that some aspects of poor health or functioning might remain hidden to the measurement process; and
- recognise that the act of measuring is, in itself, an exercise of power that potentially carries implications (for those being measured, and those doing the measuring) that reach beyond the confines of the discrete piece of analysis being conducted, and that power brings certain responsibilities.

Therefore, deciding whether to classify someone's reported symptoms of psychological distress, or their BMI above a certain threshold, or uncomplicated / non-symptomatic conditions such as hypertension, or even sub-clinical disease states such as pre-diabetes as health conditions is not simply a data processing task, but is instead an act that requires considerable prior thought and justification.

Chapter 5 Identifying people with multiple conditions: integrating theory and data

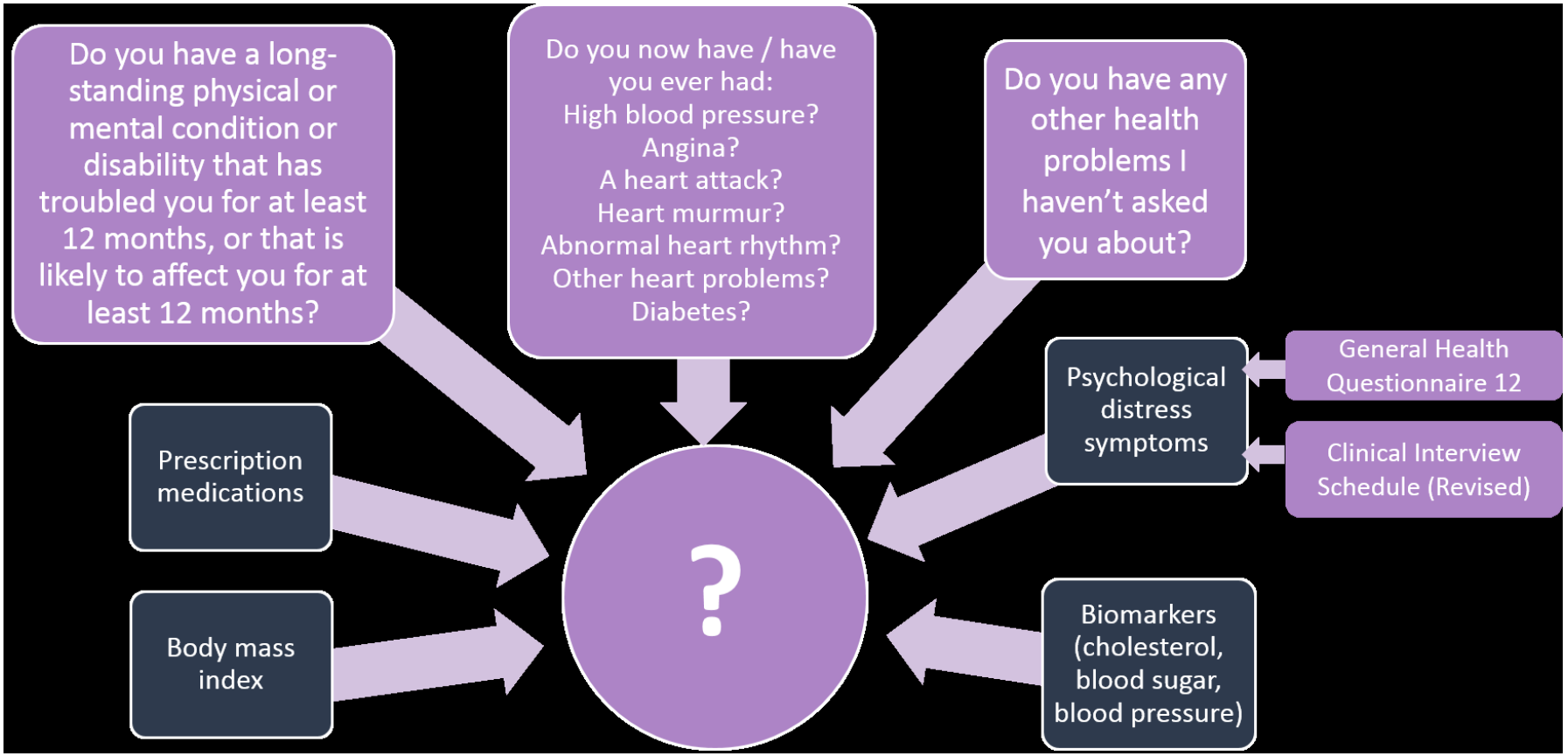
Introduction

The previous chapters should, by now, have clearly illustrated that the definition and identification of conditions (and multiples of them) is not a straightforward process. This chapter presents the outcome of applying the theoretical insights reviewed in Chapter 4 to the data collected in the survey, in order to identify adults in Scotland living with multiple health conditions.

Chapter 3 outlined the wide array of data that could *potentially* be used to identify health conditions. Figure 5.1 provides a summary of these. The purple boxes highlight questions that were asked directly of participants, the dark blue boxes illustrate additional information from which the presence of conditions could potentially be inferred (e.g. via biomarkers such as blood samples, BMI, or information on prescriptions). Each of these sets of data are considered in turn in this chapter. The issues that they present for the measurement of multiple conditions are outlined and the results of any further analysis conducted to inform the decision about their inclusion are presented. A summary of the decision made for each set of data is then provided. The last part of the chapter then presents the impact of the new definition arrived at on prevalence of multiple conditions, overall and for key sub-groups in the population. The next chapter then takes this definition and explores the life experiences of people with multiple conditions in more detail.

In amongst the various conceptual and measurement challenges outlined in Chapter 2, it was noted that Fortin et al. (2012) recommended that multiplicity be defined as both two or more, and three or more, conditions, in order to better delineate the experiences of older populations. However, in line with the majority of the literature in this field, and to enable comparisons to be more easily drawn between the estimates generated here and those published in other sources, a threshold of two or more has been used throughout.

Figure 5.1 Overview of health conditions data in SHeS 2008-2011

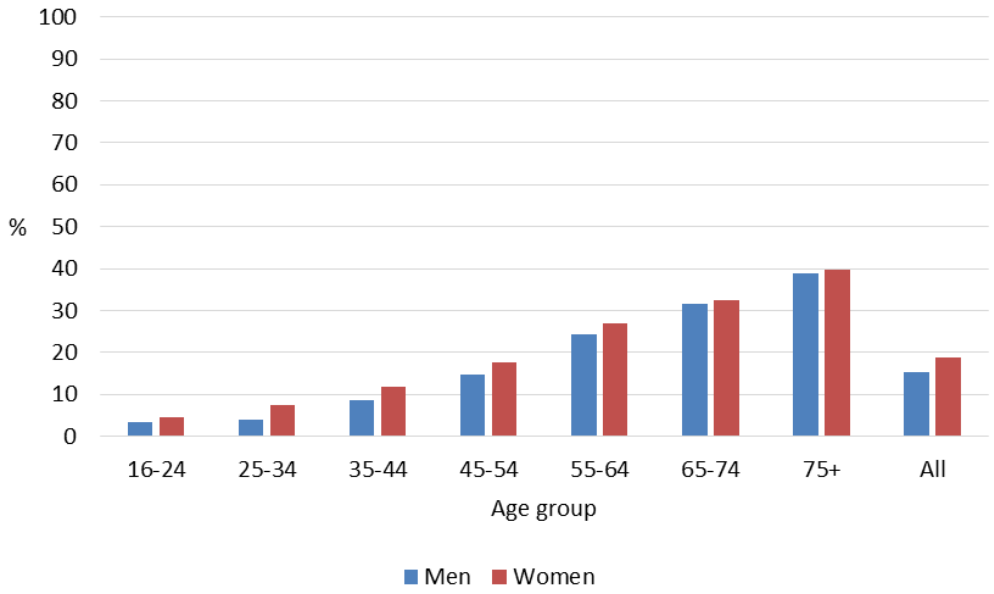


Long-term conditions: unprompted

Summary of prevalence

In 2008-2011, based on the question that asked people to report long-term conditions (LTC) without any prompting, 17.2% of adults aged 16 and over in Scotland reported two or more, 24.9% reported one condition, and 57.9% said they had none. Prevalence of multiple conditions was a little higher in women (18.8%) than men (15.5%). As Figure 5.2 illustrates, prevalence increased markedly with age, though at no point did a majority of any age group have multiple conditions. The extent to which this corresponds with prevalence estimates from other sources (e.g. in Barnett et al. (2012) or McLean et al. (2014)) is discussed at the end of the chapter.

Figure 5.2 Prevalence of multiple long-term conditions (unprompted question) in adults aged 16 and over, by sex and age group, SHeS 2008-2011



As noted in Chapter 3, the individual conditions reported were coded and then aggregated to correspond with ICD 10 chapters. The prevalence of condition types, based on this classification, is shown in Table 5.1. The two most commonly reported condition types were those affecting the musculoskeletal (16.7%) and circulatory (10.9%) systems.

Table 5.1 Prevalence of conditions by ICD 10 chapter, adults aged 16 and over, by sex, SHeS 2008-2011

	Men	Women	All adults (16+)
ICD 10 chapter	**%**	**%**	**%**
I Infectious disease	0.2	0.2	0.2
II Neoplasms & benign growths	1.8	2.0	1.9
III Blood & related organs	0.5	1.3	0.9
IV Endocrine & metabolic disorders	6.2	8.2	7.2
V Mental health conditions	5.0	7.1	6.1
VI Nervous system disorders	3.7	4.7	4.2
VII Eye complaints	1.8	1.8	1.8
VIII Ear complaints	1.8	1.8	1.8
IX Heart & circulatory system	11.2	10.5	10.9
X Respiratory system	7.6	7.6	7.6
XI Digestive system	3.8	4.9	4.3
XII Skin complaints	1.4	1.4	1.4
XIII Musculoskeletal system	15.0	18.2	16.7
XIV Genito-urinary system	1.7	1.9	1.8
XVIII Other complaints	0.3	0.3	0.3
Sample size	*12,516*	*16,256*	*28,772*

Note: Percentages are weighted, sample sizes are unweighted

Issues to be resolved

The overview of the information collected at the unprompted LTC question, and the coding applied, presented in Chapter 3, revealed two key issues that needed to be resolved to ensure that the data reflected people's condition status as accurately as possible:

1. The aggregation of multiple conditions with the same code; and
2. The aggregation of individual condition codes into ICD chapter-level groups.

These acts transform the information collected directly from participants into data items for specific reporting purposes, but they clearly have the potential to lose some of the more finely grained information about people's illness experiences. However, if the two reported conditions were more akin to two sets of symptoms related to one condition (e.g. pain and immobility as a consequence of arthritis), rather than two distinct, and therefore multiply experienced, conditions, removing the aggregation could add more noise than signal. For example, the discussion in Chapter 4 of problems associated with the diagnosis and classification of mental health problems highlighted the fact that dispute surrounds the distinction between anxiety and

depression. Horwitz (2011) describes them instead as symptoms of a single overarching syndrome or vulnerability. However, the collective insights discussed in Chapter 4 surrounding illness classification and the experiences of people living with long-term conditions, and in particular the profound disruption to lives that can accompany diagnoses, coupled with a concern not to privilege one set of accounts over others, led me to be distinctly uncomfortable with the idea of aggregating conditions with the same codes, or within the same ICD chapters, and counting them only once, without first inspecting the answers and coding directly.

To explore the impact of the two stages of aggregation, the data were re-processed to remove the aggregation (adapting the syntax documented in the derived variable specification supplied with the public dataset, see Appendix F). This, alongside access to the anonymised free-text data, enabled me to see what kinds of conditions ended up being aggregated, and what impact it made on overall population estimates. In total, 26 of the 40 condition codes were used more than once for the same individual. A selection of the most common conditions for which multiple codes were applied is presented in Table 5.2. (Note that these figures relate to the raw frequencies in the dataset, not weighted population prevalence estimates, and therefore do not match the figures in Table 5.1 above). Unsurprisingly, the mental illness code (which, as already discussed, covers a broad range of conditions) was the most commonly applied on multiple occasions for the same individual: 6.2% of participants overall had a condition coded as a mental illness, just under 10% of whom had in fact mentioned more than one such condition (the majority of whom mentioned two). The next most commonly multiply-applied code was for "other problems of bones/joints/muscles", where just under 6% of people with such a condition having mentioned more than one.

Table 5.2 Prevalence of the same long-term condition codes being used more than once for same individual (selected conditions), SHeS 2008-2011

	Mental illness		Other problems of bones/joints/ muscles		Other endocrine system		Other nervous system problems		Arthritis	
	%	n	%	n	%	n	%	n	%	n
Total with condition	6.2	1782	7.6	2169	4.3	1241	3.3	936	9.3	2665
No. of codes applied										
One	90.3	1609	94.4	2056	95.2	1182	95.6	895	97.4	2596
Two	8.3	148	5.1	112	4.7	58	4.3	40	2.6	69
Three	1.2	22	0.4	0	0.1	1	0.1	1	-	-
Four	0.1	2	0.0	1	-	-	-	-	-	-
Five	-	-	-	-	-	-	-	-	-	-
Six	0.1	1	-	-	-	-	-	-	-	-

Note: Percentages and sample sizes are unweighted

The most important points to note from Table 5.2 are that multiple uses of the same condition codes was generally rare, and that where it did happen to any great extent (e.g. in 5% of cases and above), the condition codes were themselves very broad and covered a number of distinct – though linked – conditions. Table 5.3 provides some examples from the free text data that help to illustrate the kinds of conditions that were coded multiple times, but which prior to the disaggregation process, would have originally only been counted as one condition.

Table 5.3 Examples of multiple conditions with the same code reported within the same individual, SHeS 2008-2011

Sex / age group	Conditions
	Mental illness/anxiety/depression/nerves
Male, 35-44	Schizophrenia + alcoholism
Male, 45-54	Bipolar depression + obsessive compulsive disorder
Male, 45-54	Alcoholism + agoraphobia
Male, 35-44	Asperger's syndrome + dyslexia + anxiety + depression
Female, 35-44	Agoraphobia + paranoia + methadone treatment
Female, 55-64	Depression + panic attacks + anxiety
	Other problems of bones/joints/muscles
Male, 55-64	Below knee amputation + other ankle needs surgery
Female, 55-64	Right hip replaced twice + left hip requires surgery
Female, 55-64	Osteoarthritis of knee + rheumatoid arthritis of hand
Female, 75+	Arthritis + polymyalgia rheumatica

With the number of multiply coded cases being so small numerically, the impact of this disaggregation on overall population prevalence would be limited. However, the fact that it occurred most commonly for the codes that were quite broad, and the examples highlighted in Table 5.3 show that people were indeed mentioning illness experiences that could appropriately be described as multiple rather than singular, suggests that disaggregating the data in this way reveals additional insights that have been lost as part of the data processing. Even if the impact was minimal, following the principle that the data should reflect, as closely as possible, people's illness experiences meant that I decided this was an important step to take.

Having made the decision to count all conditions with identical codes as discrete entities, the same logic was then applied to the chapter-level disaggregation. Table 5.4 shows the prevalence of reporting multiple conditions under the same ICD chapter headings, for the four most common chapters with four or more associated codes. Prevalence of reporting multiple conditions within these chapters ranged from 13% for musculoskeletal conditions to somewhat less, 6.5%, for digestive system conditions.

Table 5.4 Number of conditions reported within selected ICD 10 chapter codes, adults aged 16 and over, SHeS 2008-2011

	ICD 10 Chapter							
	Musculo-skeletal		Circulatory		Respiratory		Digestive	
Number of conditions reported	**%**	**N**	**%**	**N**	**%**	**N**	**%**	**N**
One	87.0	4745	88.2	3226	94.1	2110	93.6	1238
Two	12.4	679	11.0	403	5.6	126	6.3	83
Three or more	0.6	33	0.9	30	0.3	6	0.2	2
Sample size		*5457*		*3659*		*2242*		*1323*

Note: Percentages and sample sizes are unweighted

Comparing the figures in Tables 5.4 and 5.3 shows that many more people "lost" an additional condition in the process of aggregating codes into chapters than did so when multiple identical codes were aggregated. This is reflected in the net change figures presented in Table 5.5 which show that ungrouping the chapters, and therefore counting conditions based on the 40 underlying codes, not the 15 grouped chapters, had more of an impact on the prevalence of multiple conditions than did the disaggregation of duplicate codes. As the final rows in the table show, together they result in around an additional 2% of people being classified as having multiple conditions (10% of all those with conditions).

Table 5.5 Impact of disaggregating the long-term conditions data on estimates of numbers of conditions (all adults), SHeS 2008-2011

All adults 16+ with a condition	(A) Grouped chapters, condition codes counted once		(B) Ungrouped chapters, condition codes counted once		(C) Ungrouped chapters & all condition codes counted		Net change		
Number of conditions	**%**	**n**	**%**	**n**	**%**	**n**	**B-A**	**C-B**	**C-A**
0	57.9	*15,617*	57.9	*15,617*	57.9	*15,617*	n/a	n/a	n/a
1	24.9	*7,546*	23.5	*7,090*	23.0	*6,923*	-1.4	-0.5	-1.9
2	11.2	*3,593*	10.9	*3,520*	10.9	*3,506*	-0.3	0	-0.3
3	4.3	*1,445*	4.9	*1,605*	5.0	*1,644*	0.6	0.1	0.7
4	1.3	*447*	1.8	*600*	1.9	*641*	0.5	0.1	0.6
5	0.3	*113*	0.7	*248*	0.8	*279*	0.4	0.1	0.5
6	0.0	*11*	0.3	*92*	0.5	*162*	0.3	0.2	0.5
2+	17.2	*5,609*	18.5	*6,065*	19.1	*6,232*	1.3	0.6	1.9
Mean conditions[a]	1.6	*13,155*	1.7	*13,155*	1.8	*13,155*	0.1	0.1	0.2
Median	1.0		1.0		1.0		n/a	n/a	n/a

Note: Percentages are weighted, sample sizes are unweighted.
[a]Mean and median conditions numbers are based on all those with a condition.

Overall, 6% of people were identified as having an additional long-term condition once the data were completely disaggregated. Of these people, most (83%) had just one additional condition, while 15% had two, and the remaining 2% had up to five more. Perhaps more critically, a third (33%) were newly classified as having two or more conditions as a result of this process, while the remaining two-thirds already had two or more conditions before the disaggregation. This means that the process more often added information about the *extent* of conditions among people who already had multiple conditions, rather than uncovering evidence of multiple conditions that was masked by the aggregation process.

Summary of outcome

All conditions mentioned, whether they attracted the same codes, or were grouped within the same ICD chapter, were counted as discrete entities for the purpose of identifying people with multiple conditions.

Table 5.6 Impact on multiple conditions prevalence of ungrouping chapters and counting all conditions, SHeS 2008-2011

	Original	Ungrouped chapters and all conditions counted
Number of conditions	**%**	**%**
None	57.9	57.9
One	24.9	23.0
Two or more	17.2	19.1
-No change	-	*13.2*
-newly identified	-	*1.9*
-extended	-	*3.9*
Mean no. of conditions[a]	1.6	1.8
Median	1.0	1.0
Sample size		
All adults 16+: 28,772		
All with conditions: 13,155		

Note: Percentages are weighted, sample sizes are unweighted.
[a]Mean and median conditions numbers are based on all those with a condition.

Specific named conditions

Summary of prevalence

The prevalence of directly reported, doctor-confirmed, CVD conditions is shown in Table 5.7. Hypertension was by far the most commonly reported condition. The figures here are for those defined as currently having hypertension, based either on their receipt of treatment or reported hypertension status, not the lifetime prevalence of ever having been diagnosed with this. As described in Chapter 3, recent incidence of stroke, heart attack and angina was established as well as lifetime prevalence.

Table 5.7 Prevalence of doctor-diagnosed named CVD conditions, adults aged 16 and over, by sex, SHeS 2008-2011

	Men	Women	All adults (16+)
CVD condition	**%**	**%**	**%**
Hypertension (current)	17.6	19.0	18.3
Diabetes	6.0	4.5	5.2
Angina			
Ever	5.1	4.4	4.8
In past 12 months	2.8	2.7	2.8
Myocardial infarction			
Ever	4.5	2.3	3.3
In past 12 months	0.6	0.3	0.4
Stroke			
Ever	2.9	2.6	2.7
In past 12 months	0.5	0.3	0.4
Sample size[a]	*12,435-12,526*	*16,145-16,259*	*28,580-28,785*

Note: Percentages are weighted, sample sizes are unweighted
[a]Sample sizes vary due to different levels of non-response for each question, figures shown are the lowest and highest of the range.

Concordance between unprompted LTC and CVD condition reporting

Given the nature of the conditions covered by the CVD questions it might be reasonable to expect there to be a high degree of overlap between the answers given to these and the previous, unprompted, LTC question. However, analysis of the answers given revealed a significant degree of discordance between responses which, in common with previous studies (Johnston et al. 2009), suggest that relying solely on the initial LTC question leads to a significant underestimate of the conditions people live with. To illustrate, 5.3% of adults reported hypertension at the LTC question but 18.3% were classified as having current hypertension based on the directly asked questions set out in Figure 3.3 (Chapter 3).

The results presented in Table 5.8 highlight the extent of the discordance between the reporting for a selection of the conditions. It shows that while the majority of people who reported a condition at the LTC question also mentioned it when asked about it directly; the reverse was not the case. The kappa statistic, reported in the final column, provides a numeric summary of the degree of agreement between the two sets of data:

0 would indicate none, 1 would be perfect agreement (Kirkwood & Sterne 2003). As outlined in Figure 3.3 (Chapter 3), historic (no longer present) conditions have been excluded, as far as possible, from the directly-reported hypertension and diabetes definitions by excluding women who only reported these conditions during pregnancy, while for hypertension, people were only included in this analysis if they said they were currently being treated for it, or who reported still having high blood pressure without treatment. Results for stroke and MI/angina are presented separately for those with events in the previous 12 months and those occurring longer ago.

Table 5.8 Correspondence between unprompted and directly reported conditions, SHeS 2008-2011

	Proportion of those who mentioned a long-term condition, who also directly-reported a doctor diagnosis of it	Proportion of those with directly-reported doctor-diagnosed conditions, who also mentioned them as a long-term condition	Level of agreement (Kappa value)
Condition	**%**	**%**	
Hypertension	98	28	Moderate-poor (0.39)
Diabetes	97	73	Excellent (0.83)
Stroke ever	92	31	Fair-good (0.46)
Within past year[a]		49	n/a
Over a year ago		28	n/a
Heart attack or angina	97	31	Fair-good (0.45)
Within past year		46	n/a
Over a year ago		17	n/a

[a]The LTC question did not record when stroke, heart attack or angina had occurred so Kappa values can't be estimated for these separately.

Note: Appendix J, Table J1 provides a comparison of 2008-2011 and 2012-2013 results for hypertension and diabetes (for the discussion in Chapter 7).

Clearly there will be many reasons underlying such discrepancies, some of which could indicate that people's understanding of the LTC question did not match the intentions of the survey designers' (a rationale aligned with the Total Survey Quality framework discussed in Chapter 3). In contrast, the fact that the discrepancy reduced somewhat for stroke, MI and angina when cases occurring more than a year ago were excluded, suggests that some of these reported diagnoses related to experiences that had perhaps ceased to have immediate consequences for people. However, much of the discussion in Chapter 4 of the nature and meaning of disease, classification,

medicalisation, overdiagnosis and illness experiences, instead highlights an alternative set of factors, beyond simple comprehension of survey instruments, that might lead to people's interpretation of questions about their health varying in the ways illustrated here. Hypertension is perhaps the most telling example of this. Most epidemiological studies of multiple conditions in the literature include hypertension in their definition, but the results here suggest that while people acknowledge they have raised blood pressure, they don't necessarily identify with it as a long-term condition in the way it tends to be framed clinically. However, the fact that someone doesn't report a condition in these terms does not, of course, mean it has no consequences for their lives, either in terms of how they engage with the work of being treated for a condition (e.g. by taking medication, making lifestyle changes and undergoing frequent monitoring), or more seriously in terms of the long-term consequences for their health.

Issues to be resolved

The key issue arising from the discrepancies described above is whether to add these directly reported conditions to the measure based on the LTC question (thus increasing the number of conditions included). My initial concern with taking this approach was whether it could be seen as privileging clinical definitions over people's self-reported, unprompted illness experiences. The LTC question does, after all, ask people to report conditions that "trouble" or "affect" them, so it might well be appropriate to exclude uncomplicated hypertension and diabetes from a measure of multiple conditions that is attempting to reflect lived experiences. However, it is also true that the conditions included under this heading can be associated with significant treatment burdens and adjustments to life (including to people's identities), following their onset. Another concern lies with the potential for overdiagnosing people at the less severe end of the disease spectrum, especially in relation to hypertension, thereby adding significant additional heterogeneity to the multiple conditions measure, resulting in a definition that has much less potential to reflect the experiences of people with more severe needs (as Aronowitz (2009) cautioned against). Of the conditions under scrutiny here, hypertension arguably was the one with the most problematic status as it showed the largest reporting discrepancy. It therefore

warranted further investigation via survival analysis using the 1998 survey data linked to mortality records.

Longitudinal analysis of undeclared hypertension

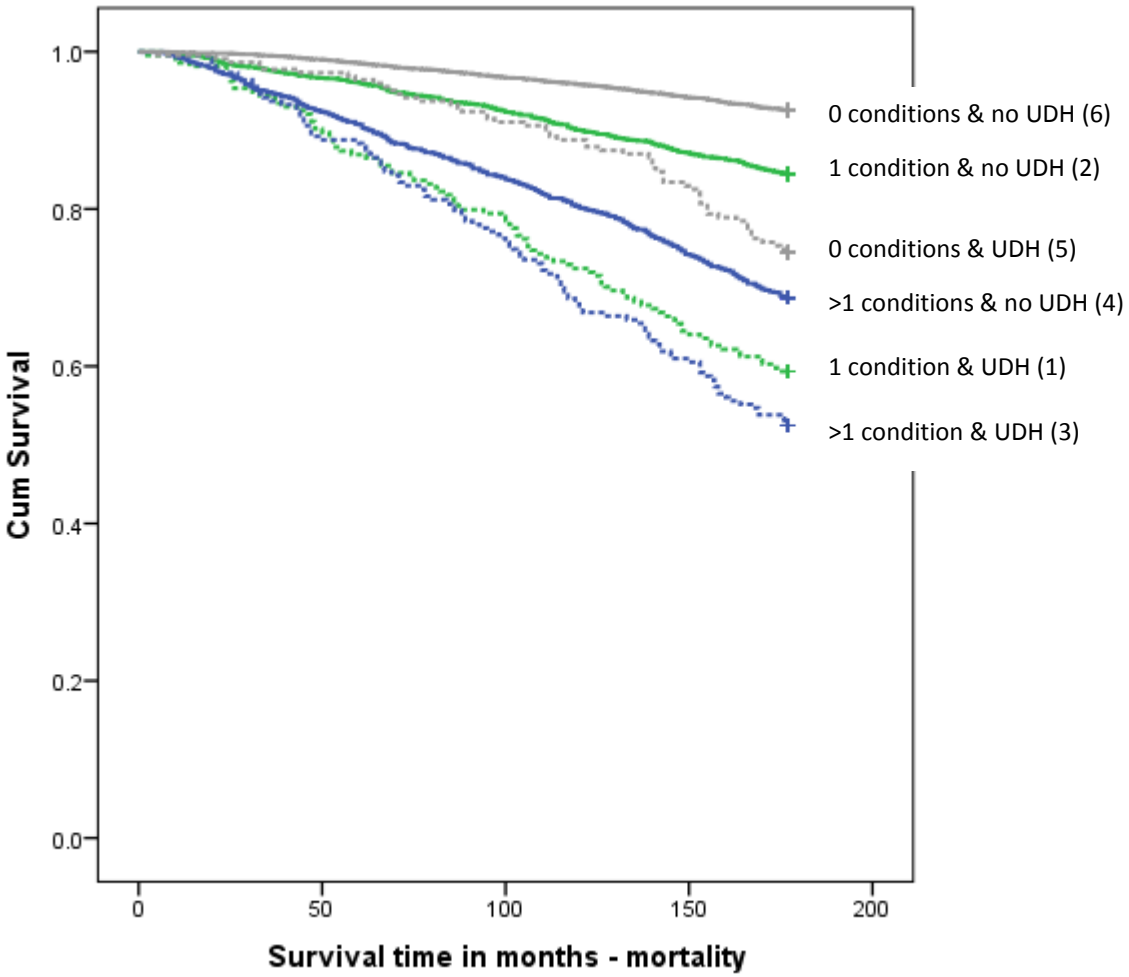
The following six groups were identified from among adults aged 16-74 and over who participated in the 1998 survey and agreed to their data being linked to NHS and mortality records. People classified as having undeclared hypertension (UDH) in this analysis obviously hadn't mentioned hypertension as an LTC, while some of the people with conditions and no UDH will have done:

1. **One long-term condition, and undeclared hypertension (UDH)**
2. One long-term condition, no undeclared hypertension (no UDH)
3. Two or more long-term conditions, and undeclared hypertension (UDH)
4. Two or more long-term conditions, no undeclared hypertension (no UDH)
5. No long-term conditions, and undeclared hypertension (UDH)
6. No long-term conditions, no undeclared hypertension (no UDH)

These groups' mortality risk (all-cause) over 14 years and 9 months of follow-up was assessed using survival analysis in the form of Kaplan-Meier plots and Cox proportional hazard modelling. Group 1 was clearly of most interest in this analysis as they represent the people who would be newly counted as having multiple conditions if their undeclared hypertension was included in the definition. If their mortality risk was akin to that seen for the existing two groups of people with multiple conditions (groups 3 and 4) this would suggest that it could be justified to re-classify them as having multiple conditions on the grounds of their shared health consequences / experiences. In addition, if survival was demonstrably lower among people already identified as having multiple conditions but who also had undeclared hypertension this would suggest that its addition to the overall measure would better capture their overall health status and disease burden. If, however, the people in group 1 had a survival profile more similar to people with one condition or none (groups 2, 5 and 6), it might suggest that re-classifying them would potentially diminish the multiple condition measure by including a reasonably large group of demonstrably healthier people.

The Kaplan-Meier survival plot in Figure 5.3 shows the cumulative survival trajectories for each of the six groups (the key group of interest, 1, has a dotted green line). The first point to note is that mortality risk increased in line with increasing condition numbers, but that undeclared hypertension was also strongly associated with increased risk of mortality. The people who reported no conditions at all had the highest probability of survival, while the group with multiple long-term conditions and undeclared hypertension (group 3) had the lowest. At the beginning of the follow-up period, up to around 50 months, group 1's survival curve was indistinguishable from those of the two groups with multiple conditions (groups 3 and 4). From around 50 months onwards survival became progressively less likely for groups 1 and 3. These patterns clearly demonstrate that people with undeclared hypertension have a higher risk of death, particularly if other conditions are also present.

Figure 5.3 Kaplan-Meier plot of survival among adults aged 16-74, for the six long-term condition and undeclared hypertension (UDH) status groups (14.9 years' follow-up), SHeS 1998-SMR linked data



An obvious explanation for these patterns would, of course, be confounding by age – if group 1's age profile was older than the other groups' then this increased risk of mortality could simply be a function of that. To explore this, additional analysis was required that could take account of these potential confounders. The obvious choice would be to estimate Cox proportional hazards ratios (CPHR) for groups 1-5, with their risk of mortality compared to group 6's (no conditions, no hypertension), first with no adjustments and secondly following adjustment for age and sex. However, the lines in the Kaplan-Meier plot above, and in the log-log plots shown in Appendix G, indicate that the proportional hazards assumption has not been met with these data (the lines cross at different points over time). Therefore, instead of estimating CPHRs,

odds ratios (OR) were estimated with death as the outcome, using binary logistic regression. An OR lacks the additional sophistication of factoring in time to events, as a CPHR does, so would not be the ideal choice of measure if the primary focus of this thesis was to explore the association between multiple conditions and mortality. However, as a mechanism for exploring whether the different groups identified above have different mortality risks, in order to help inform decisions about how to define multiple conditions, the odds ratios presented in Table 5.9 meet this purpose. They show that while this adjustment did indeed reduce the risk of mortality for group 1 notably, their OR remained closer to those for the two groups already defined as having multiple conditions.[19]

Table 5.9 Unadjusted and adjusted ORs for mortality in adults aged 16-74 at baseline, by condition number and undeclared hypertension status, SHeS 1998-SMR linked data

Condition / directly reported hypertension status **(reference group: no conditions, no undeclared hypertension)**	**Unadjusted OR**	**95% CI[a]**	**Adjusted OR (sex and age)**	**95% CI[a]**
(1) One long-term condition, and undeclared hypertension	**10.7**	**7.7-14.8**	**2.9**	**2.0-4.2**
(2) One long-term condition, no undeclared hypertension	2.5	2.1-3.0	1.6	1.3-1.9
(3) Two or more long-term conditions, and undeclared hypertension	12.8	9.3-17.6	3.5	2.5-5.0
(4) Two or more long-term conditions, no undeclared hypertension	6.4	5.3-7.8	2.6	2.1-3.2
(5) No long-term conditions, and undeclared hypertension	5.0	3.5-7.2	1.3	0.9-2.0 [n.s.]

[a]p value for all ORs $\leq$0.001, unless otherwise stated.

These analyses were conducted to help inform the decision about whether to include these additional cases of hypertension in the multiple conditions measure. Viewed

[19] CPHRs were also estimated and, despite the problem with the non-proportional risks, these results showed almost identical overall patterns.

solely through a clinical lens this additional analysis could be seen as unnecessary: hypertension is a known risk factor for cardio-vascular events and mortality, as reflected by the fact its identification and treatment is incentivised through the Quality Outcomes Framework (QOF) which currently generates part of the income for GP practices (ISD Scotland 2010a). However, the additional insights provided by the sociological perspectives outlined in Chapter 4 raised sufficient questions about its status to warrant it first being subject to this further scrutiny.

Diabetes, stroke, MI and angina were also subject to varying degrees of under-reporting (as shown in Table 5.8). Overall, however, the numbers of cases were too small to enable the survival analysis presented above to be replicated for these conditions. Instead, the decision to include these conditions was taken on the basis of their likely treatment and life burden.

Summary of outcome

The following reported doctor-diagnosed conditions that had not been mentioned unprompted as long-term conditions were included in the definition of multiple conditions:

- hypertension (if currently treated, or if untreated, still high; excluding pregnancy-related cases);
- diabetes (excluding pregnancy-related);
- MI, angina or stroke if occurred within the past 12 months.

The timing stipulation was included for MI, stroke and angina due to the possibility that people not mentioning these if they occurred more than 12 months ago had reached a point of recovery where they no longer imposed a significant burden on the participants (either physically or psychologically).

Table 5.10 Impact on multiple conditions prevalence of adding previously unmentioned doctor-diagnoses of diabetes, hypertension, stroke/MI/angina (in past 12 months), SHeS 2008-2011

	Original	Addition of: diabetes, hypertension, stroke/MI/angina (in past 12 months)
Number of conditions	**%**	**%**
None	57.9	52.7
One	24.9	23.8
Two or more	17.2	23.4
-No change	-	9.7
-newly identified	-	6.3
-extended	-	7.5
Mean no. of conditions[a]	1.6	1.9
Median	1.0	1.0
Sample size		
All adults 16+: 28,772		
All with conditions: 13,155		

[a]Mean & median no. of conditions is based only on those with conditions.
Note: Percentages are weighted, sample sizes are unweighted.

Other health problems

Summary of prevalence

Other health problems (OHP) were reported by 14.7% of adults aged 16 and over (in contrast, 42.1% of adults reported at least one LTC). A total of 4,651 OHPs were assigned a valid code, with 6% judged unclassifiable, suggesting a broader range of issues were mentioned than was the case for LTCs where <1% could not be coded. Table 5.11 presents the prevalence of conditions reported grouped by ICD 10 chapter, for those who reported having an OHP. Problems related to the musculoskeletal system were by far the most commonly reported (20.7%), followed by respiratory (13.6%), digestive (13.4%) and endocrine / metabolic (10.4%) system problems. Note that these groupings have been used for summary reporting purposes only; the data were used in their disaggregated form for all the analyses presented below and for the purposes of identifying people with multiple conditions.

Table 5.11 Prevalence of other health problems reported by ICD 10 chapter, adults aged 16 and over who reported an additional health problem, by sex, SHeS 2008-2011

	Men	Women	All adults (16+)
ICD 10 chapter	**%**	**%**	**%**
I Infectious disease	0.4	0.3	0.3
II Neoplasms & benign growths	4.0	6.0	5.1
III Blood & related organs	1.1	3.3	2.3
IV Endocrine & metabolic disorders	6.6	13.4	10.4
V Mental health conditions	5.4	6.0	5.8
VI Nervous system disorders	4.3	6.0	5.2
VII Eye complaints	5.0	3.5	4.2
VIII Ear complaints	5.0	3.2	4.0
IX Heart & circulatory system	4.2	3.8	4.0
X Respiratory system	15.0	12.4	13.6
XI Digestive system	13.8	13.0	13.4
XII Skin complaints	6.8	4.7	5.7
XIII Musculoskeletal system	23.7	18.3	20.7
XIV Genito-urinary system	6.1	9.1	7.8
XVIII Other complaints	1.0	0.7	0.8
Sample size	*1826*	*2590*	*4416*

Note: Percentages are weighted, sample sizes are unweighted.

Issues to be resolved

A cross-sectional survey, by its very nature, captures a picture of people's health at one point in time, though it can, of course, ask people to provide answers bounded by specific time periods, as the LTC question does. The OHP question wording provided no cues about the duration or severity of the problems that participants were expected to report, so there is a danger that some people would report transient issues with minimal impact. These might well have had a significant impact on people's lives while they were happening, but they are not necessarily representative of a person's longer term state of health and the challenges they may face as a consequence of living with multiple conditions on a permanent basis. Therefore, including acute episodes of ill-health, or issues that have a very low burden, would detract from this purpose.

However, it was clear from reading through the free-text answers that mentioning short-term, self-limiting health problems such as coughs, colds and 'flu was very rare – in part this would have been due to people with short-term illnesses delaying their interview until they had recovered, or not participating at all. And while some arguably less burdensome conditions were reported (for example, in one case, dandruff) this was the exception, not the rule. It is highly likely that the series of questions about specific CVD conditions, and the long-term conditions question, framed the responses provided about "other health problems" by priming participants to focus more on ongoing health issues, rather than brief episodes of ill-health. Bradburn (2004) provides a detailed account of the question-answering process in surveys and describes how priming:

> activates thoughts or 'schemata', that is, organized thoughts about objects or concepts, so that they are more accessible to consciousness and thus more easily come into play in interpreting the questions. (Bradburn 2004, p.8).

Similarly, he argues that certain kinds of information are more readily retrieved by participants if they relate to "*well rehearsed topics*" that have an existing narrative to draw on, describing them as "*chronically accessible*" (Bradburn 2004, p.10). Although he cites birth dates and marital status as examples of these kinds of topics, enduring health and illness problems can – as the discussion in Chapter 4 illustrated – become similarly integral to people's narratives and are therefore likely to also fall into the category of "*chronically accessible*" information.

The chronic accessibility of more burdensome health problems might help explain why transient and very low burden issues tended not to be reported, but it doesn't explain why some people with the same conditions – that by their nature are long-term – reported them as such while others reported them as an "other health problem". The key issue to be resolved was therefore the fact that some of the problems reported at this question clearly represented long-term and potentially burdensome conditions which, if left out of the multiple conditions measure would underrepresent the extent of people's condition burden, but some did not really meet this criteria. Excluding this information would therefore under-represent some people's illness burden; however, including all the information would afford too much status and equivalence to some

very minor health issues, thus diminishing the overall measure's ability to identify a meaningfully coherent sub-group in the population living with multiple conditions.

Comparison of conditions reported as long-term and as other health problems

Symptoms or diagnoses?

One way of assessing the information provided across the two questions was to examine the nature of the descriptions people gave. The LTC question was framed around specific conditions whereas the OHP question, in asking about "problems" could be open to interpretation and perhaps generate more information about underlying symptoms than about diagnoses. While symptoms might more closely reflect people's lived experiences of health problems, converting these into meaningful information about the extent of people's multiple condition burden would be difficult. For example, someone might have reported arthritis as a long-term health condition, but then talked about its pain and associated complications as another health problem – so these two distinct sets of information would not represent two discrete conditions.

As detailed in Chapter 3, random sub-samples of 1,000 cases with LTC and OHP free-text answers were selected to enable detailed analysis of their contents to be conducted. The first reported condition was reviewed and coded using the code frames shown in Table 5.12.

Information about LTCs was recorded using specific named conditions 75% of the time, rather than descriptions of symptoms. A slightly lower proportion, 67%, of OHPs involved named conditions, though still clearly a majority. In contrast, 10% of LTC and 14% of OHP information related to symptoms. The concern that the OHP information provided was universally insufficiently specific (or distinct from the LTC information) for the purposes of identifying additional conditions could therefore be largely rejected on the grounds that the *nature* of the information reported was broadly similar across the two questions.

Table 5.12 Classification of free-text answers on LTCs and OHPs, SHeS 2008-2011

	LTC	OHP
Classification of condition description	**%**	**%**
Specific named condition	75	67
Broad condition / body system	10	7
Symptom	10	14
Treatment	2	3
Injury	2	2
Mixture / other	1	1
Still under investigation	n/a	3
Historic / in remission	n/a	1
Sample size	*1,000*	*1,000*

Note: Percentages and sample sizes are unweighted.

Comparison of LTC and OHP reporting

The balance of condition reporting across the two question types was explored by creating combined measures of conditions based on the data from both sources and then assessing what proportion of cases had been reported as LTC or OHP, or both. Table 5.13 presents the results for a selection of conditions. Note that where codes covered specific single conditions (rather than broader groupings), duplicate reporting was prevented at the coding stage, but where the code covered a broad range, then it was plausible for someone to have the same condition code recorded at the LTC and OHP questions, but related to different conditions. The figures presented are clearly not exhaustive in terms of all the possible conditions covered in the survey, but it provides sufficient evidence of the fact that the LTC question alone did not capture the full extent of people's on-going ill-health burden.

Interesting variations existed across the condition types, for example around 90% of arthritis and mental health conditions were reported as long-term, compared with just 60% in the case of high cholesterol.[20] The neoplasms category is perhaps the most

[20] High cholesterol and thyroid problems are covered by the same "other endocrine/ metabolic" conditions code. The relatively high proportion of cases with this code among the OHP cases led to a re-coding exercise to distinguish between high cholesterol, thyroid problems (under or over activity) and other problems. The analysis in Table 5-13 is based on this new variable.

interesting; reviewing the free-text answers suggested that some of the cases reported as other health problems (as opposed to long-term conditions) were in fact cancers in remission (with varying lengths of time since treatment stopped), while others were benign cysts or lumps currently under investigation. However, there were also clear cases of non-benign cancer currently undergoing treatment. This analysis cannot reveal why some people did not report cancer that was being treated when asked about long-term conditions, but the significance of a cancer diagnosis, and the typical burden of the treatment required, makes it unlikely that participants had forgotten about their condition when asked the earlier question. It is possible that stipulating a 12 month or longer duration perhaps implied a degree of permanency that some people with cancer did not want to acknowledge, or it could simply have been a failure of the question wording – note that it did not include the term "illness" – which led to participants not reporting such conditions.

Table 5.13 Whether conditions were reported as long-term or other health problems, for a selection of conditions, SHeS 2008-2011

		What condition was reported as			
Condition type		**LTC**	**OHP**	**Both**	***Sample size***
Arthritis	%	90	9	0.4	*2938*
Mental health conditions	%	88	10	1	*1987*
Asthma	%	82	19	n/a[a]	*1800*
Thyroid problems	%	75	25	n/a[a]	*1097*
Neoplasms, lumps, cysts	%	72	27	1	*860*
High cholesterol	%	60	40	n/a[b]	*540*

Note: Percentages and sample sizes are unweighted.
[a]Single-coded condition, couldn't be included in both categories.

High cholesterol provides another interesting example. The LTC question asked people to report conditions that had "troubled" them for at least 12 months, or would be likely to affect them for that duration. The fact that four in ten people with high cholesterol mentioned these as other problems, rather than long-term conditions, will very likely reflect the fact that high cholesterol is something people can only experience

via its treatment and testing regime rather than via the symptoms the condition generates. Blood pressure (as discussed above) has similar features. The inclusion of this kind of health condition in a multiple conditions measure therefore poses a challenge: its impact is arguably low, if considered in terms of its consequences for activities of daily living, pain or treatment burden, therefore it is questionable to include it alongside considerably more intrusive conditions. However, people taking daily lipid-lowering medication, or taking steps to control it via diet or exercise, do have their life encroached upon, especially if they experience drug side-effects. In such circumstances, then, high cholesterol arguably contributes to the cumulative health burden of people faced with managing other conditions.

Longitudinal analysis of other health problems

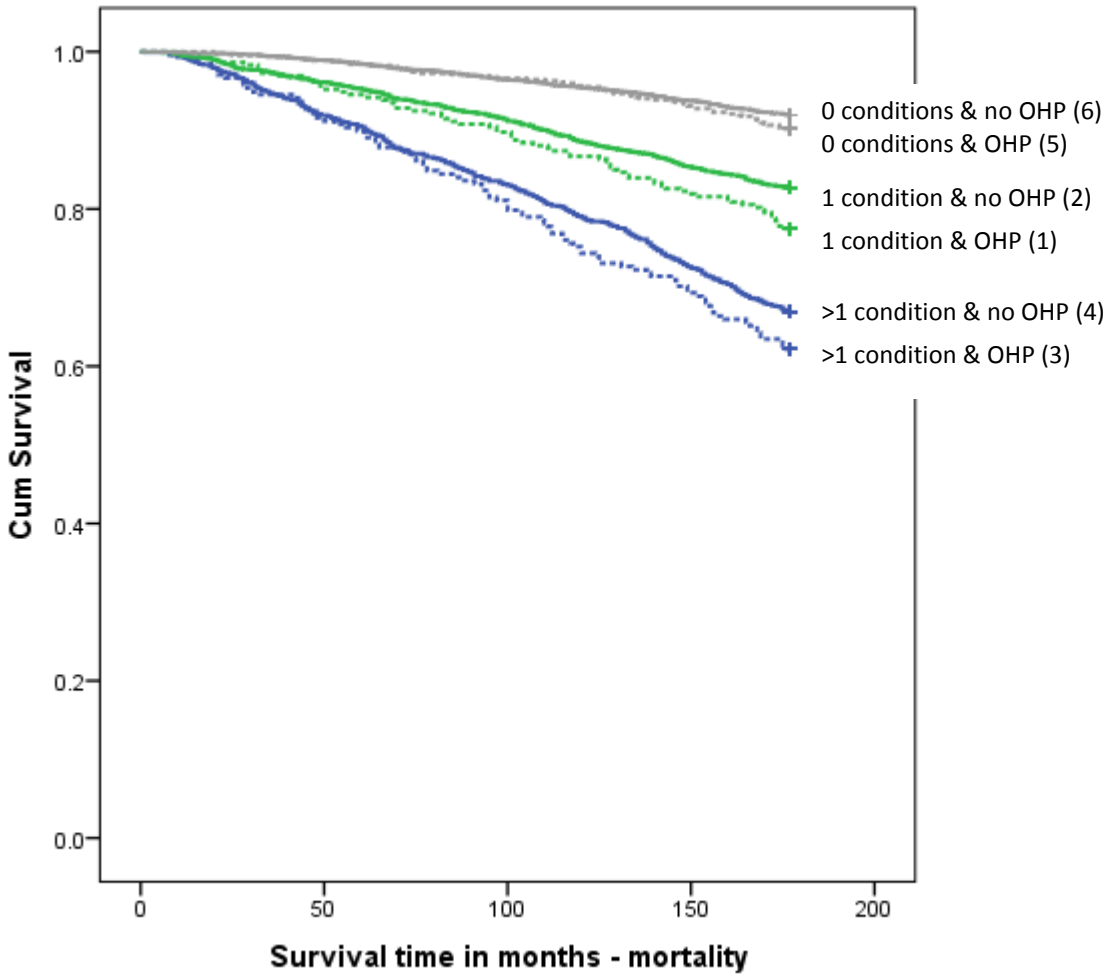
As the above should have highlighted, the OHP data included a diverse range of conditions and symptoms, with varying degrees of likely severity and impact. A blanket exclusion of these additional insights on people's health would explicitly privilege the more medically-framed questions (on LTCs and doctor-confirmed CVD conditions), at the expense of the voice of the participants themselves. A potential method of resolving the issue of how to discount less serious health problems without silencing people's experiences presented itself: by integrating the insights provided by people's global self-assessments of their health. As self-rated health has been found to be good predictor of mortality, it therefore taps an underlying reality of people's illness experiences, while its social patterning reflects morbidity and mortality gradients seen in official data (Jylhä 2009; Au & Johnston 2014).

The following approach was adopted: to help assess the longer-term impact of OHPs, and to potentially uncover the extent of their impact when compared to the long-term conditions people reported, survival analysis was conducted using the same approach undertaken for the additional hypertension data described above. This was done in two stages. Initially, the following six groups were identified from among the participants aged 16-74 who participated in the 1998 survey and agreed to record-linkage:

1. **One long-term condition, and other health problem/s**
2. One long-term condition, no other health problem/s
3. Two or more long-term conditions, and other health problem/s
4. Two or more long-term conditions, no other health problem/s
5. No long-term conditions, and other health problem/s
6. No long-term conditions, no other health problem/s

As before, group 1 (dotted green line) was of most interest – these people would be added to the multiple condition measure if all OHPs were included.

Figure 5.4 Kaplan-Meier plot of survival among adults aged 16-74 at baseline, for the six long-term condition and other health problem status groups (14.9 years' follow-up), SHeS 1998-SMR linked data



The survival plot suggests that mortality risk largely clustered around the number of long-term conditions people reported, with some additional effect evident for people who also reported other health problems, but not enough to move group 1's mortality risk closer to that seen for the people already defined as having multiple conditions. Again, due to the non-proportional hazards, logistic regression was used to quantify these risks with and without adjustment for age and sex (Table 5.14).

Table 5.14 Unadjusted and adjusted ORs for mortality in adults aged 16-74 at baseline, by long-term condition number and other health problems status, SHeS 1998-SMR linked data

Condition / other health problem status **(reference group: no conditions, no other health problems)**	**Unadjusted OR**	**95% CI[a]**	**Adjusted OR (sex and age)**	**95% CI[a]**
(1) One long-term condition, and other health problem/s	**3.9**	**2.8-5.4**	**2.1**	**1.5-3.1**
(2) One long-term condition, no other health problem/s	2.7	2.2-3.2	1.6	1.4-1.9
(3) Two or more long-term conditions, and other health problem/s	7.8	5.6-10.8	2.6	1.8-3.7
(4) Two or more long-term conditions, no other health problem/s	6.6	5.5-8.0	2.7	2.2-3.4
(5) No long-term conditions, and other health problem/s	1.5	1.1-2.0	1.1	0.8-1.5 [n.s.]

[a]p value for all ORs $\leq$0.01, unless otherwise stated.

These results confirm the concern noted throughout that adding all the OHP data would provide both signal and noise, potentially diminishing the usefulness of the overall multiple conditions measure. Therefore a second stage of the analysis was conducted. This time, a person's OHP information was only included if they also reported their general health to be less than good. In this way, people who reported additional health problems but otherwise said their health was very good, or good, did not have an extra condition added to the multiple condition measure. As Figure 5.5 illustrates, as a result of this adjustment, the survival trajectory of the people who would be newly classified as having multiple conditions was much more similar to those of the other two groups with multiple conditions. The ORs presented in Table 5.15 confirm this pattern.

Figure 5.5 Kaplan-Meier plot of survival among adults aged 16-74 at baseline, for the six long-term condition and other health problem status groups – adjusted for self-rated health (14.9 years' follow-up), SHeS 1998-SMR linked data

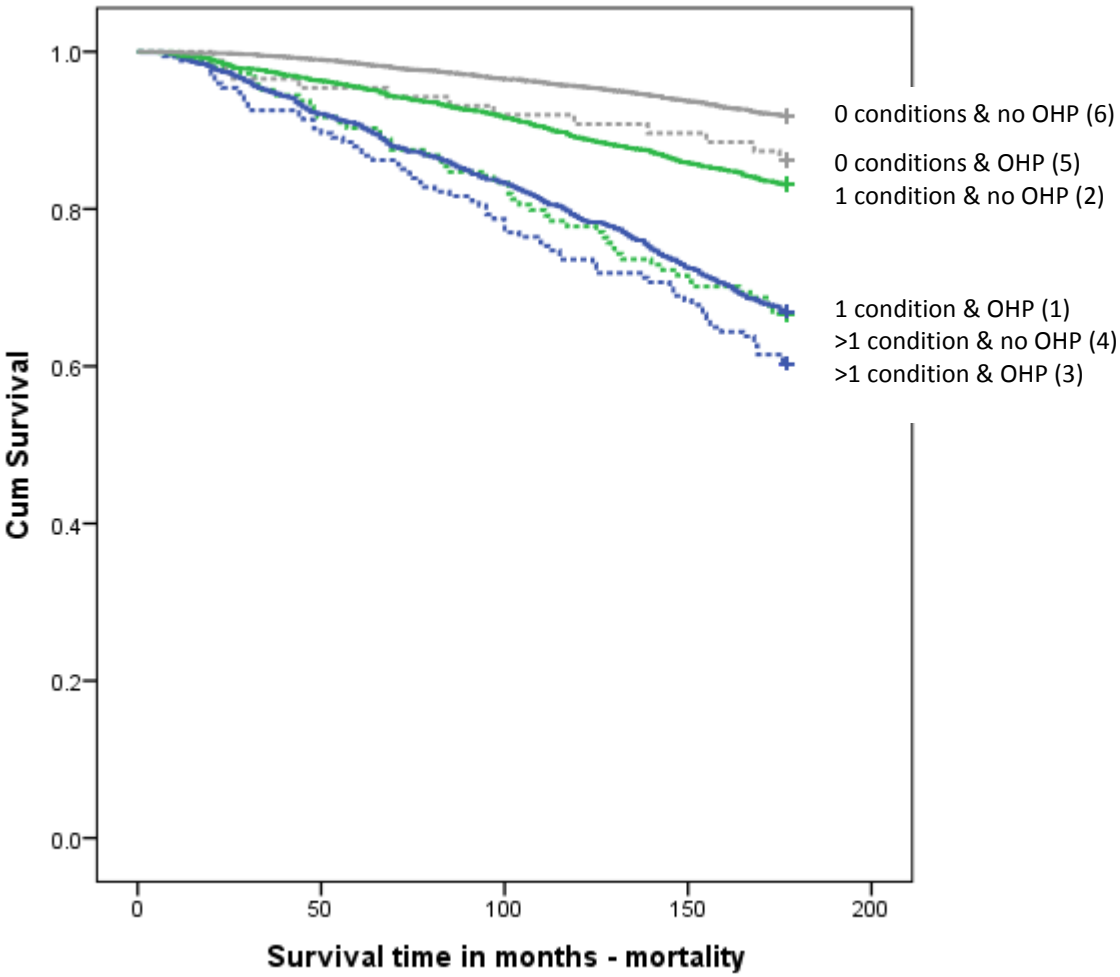


Table 5.15 Unadjusted and adjusted ORs for mortality in adults aged 16-74 at baseline, by long-term condition number and other health problems status (adjusted for self-rated health), SHeS 1998-SMR linked data

Condition / other health problem status **(reference group: no conditions, no other health problems)**	**Unadjusted OR**	**95% CI[a]**	**Adjusted OR (sex and age)**	**95% CI[a]**
(1) One long-term condition, and other health problem/s if general health <good	**7.0**	**4.7-10.5**	**3.7**	**2.3-5.8**
(2) One long-term condition, no other health problem/s	2.5	2.1-3.0	1.6	1.4-1.9
(3) Two or more long-term conditions, and other health problem/s if general health <good	8.1	5.6-11.7	2.9	1.9-4.4
(4) Two or more long-term conditions, no other health problem/s	6.4	5.3-7.6	2.7	2.2-3.3
(5) No long-term conditions, and other health problem/s if general health <good	2.2	1.1-4.2	2.0	0.9-4.3 [n.s.]

[a]p value for all ORs ≤0.02, unless otherwise stated.

Summary of outcome

Other health problems were included in the multiple conditions measure only if they were reported by people with less than good self-reported health. The impact on prevalence was as follows.

Table 5.16 Impact on multiple conditions prevalence of adding other reported health problems, SHeS 2008-2011

	Original	All other health problems added	All other health problems added if self-rated health less than good
Number of conditions	**%**	**%**	**%**
None	57.9	49.8	56.9
One	24.9	27.3	22.6
Two or more	17.2	22.9	20.6
-No change	-	11.1	11.8
-newly identified	-	5.7	3.4
-extended	-	6.0	5.3
Mean no. of conditions[a]	1.6	1.8	1.8
Median	1.0	1.0	1.0
Sample size			
All adults 16+: 28,772			
All with conditions (original): 13,155			
All with conditions (all problems added): 15,524			
All with conditions (problems added if health <good): 13,492			

Note: Percentages are weighted, sample sizes are unweighted.
[a]Mean & median no. of conditions is based only on those with conditions.

Obesity

Summary of prevalence

Table 5.17 shows that the overall prevalence of obesity (BMI ≥30 kg/m^2) in adults was 27.4%, and that the vast majority of people who fell into this category had a BMI below the more severe threshold of 40 or more.

Table 5.17 BMI groups and prevalence of obesity, adults aged 16 and over by, sex, SHeS 2008-2011

	Men	Women	All adults
BMI (kg/m^2) group[a]	**%**	**%**	**%**
Underweight (<18.5)	1.6	2.1	1.9
Healthy (18.5-<25)	30.1	36.8	33.5
Overweight (25-<30)	41.2	33.3	37.2
Obese I (30-<40)	25.6	24.3	24.9
Obese II (≥40)	1.4	3.5	2.5
All obese (≥30)	27.0	27.8	27.4
Sample size	*10,691*	*13,185*	*23,876*

Note: Percentages are weighted, sample sizes are unweighted.
[a]Table is based on all with valid height and weight measurements.

Issues to be resolved

The previous sections focused on all the conditions data collected in the survey via questions asked of participants. This section approaches the data from a new angle by addressing the issue of whether one specific condition or health state – obesity – should be included as part of the multiple conditions count. Including obesity would make use of the survey's direct measurements of height and weight, from which BMI can be derived, and people in the obese range identified.

As discussed in the case study in Chapter 4, obesity has a contested status as a disease or health condition, and its inclusion in studies of multiple conditions tends to be based on its availability to analysts rather than due to *a priori* decisions about whether it should be. SHeS included direct measurements of height and weight (conducted using a standardised protocol and calibrated equipment) from which the obesity status could be derived for participants who agreed to be weighted and measured. However, as the discussion in Chapter 4 should have highlighted, including it as a condition simply because it was measured bypasses any considerations as to whether it *should* be. While its status as a condition is increasingly common in US clinical and research practice, in the UK it is still more commonly regarded as a health *risk* – though often still requiring clinical management – so its inclusion here as a condition would stray into the territory of medicalisation of risk. Based on this, and other uncertainties related to the adequacy of the specific measure of obesity in the survey (BMI), discussed below and in Chapter 4, obesity was subjected to additional levels of scrutiny before a decision was taken on its inclusion.

Approach taken

Using the principle that people's own accounts of their health experiences should be afforded a significant voice in this process, the first step taken was an assessment of the extent to which participants themselves mentioned obesity or weight problems when asked about long-term or other health problems. Secondly, survival analysis (of the same kind used in the hypertension and OHP examples above) was conducted to see if a negative association with mortality risk existed. If so, it could be argued that obesity

should be included by virtue of its impact on people's lived experiences, regardless of any wider consensus surrounding its disease or risk status.

Did people mention obesity or weight problems when asked about their health?

Weight problems, such as obesity, did not have a distinct code within the codeframe, but if mentioned they should have been coded using the "other endocrine and metabolic conditions" code (in this context, "other" is used to distinguish this code from diabetes, the other condition code within this ICD chapter). As noted above, 27.4% of adults aged 16 and over could be classified as obese ($\geq$30 kg/m^2). In contrast, just 5.1% of adults had either a long-term condition or other health problem assigned the "other endocrine and metabolic condition" code (3.7% LTC, 1.4% OHP). However, as this code covers a number of conditions, including hyper/hypo-thyroidism and high cholesterol, further coding was required to identify cases where weight was specifically mentioned as a health condition. Of the 1,240 long-term conditions coded as "other endocrine or metabolic" just 2.0% (n=25) were the result of obesity or weight being mentioned, as were 2.4% (n=13) of the 532 other health problems with this code – which represents 0.1% of the population overall. On the basis of these figures, obesity is clearly not something that participants identified with as either a long-term condition or health problem.

The diagnostic specificity of BMI at the individual level is far from perfect, for example it cannot distinguish between muscle and fat, so a person with very developed muscles and very little body fat would have the same BMI as someone of the same height and weight who had very little muscle mass and a lot of fat. Therefore, the discrepancy between the prevalence of obesity (27%) and its very rare reporting as a health condition (0.1%), could in part be due to BMI misclassifying people's obesity status. However, this is a very large discrepancy and BMI is not *that* imperfect a measure. The Scottish Intercollegiate Guidelines Network (SIGN) classification of obesity-related disease risk recommends that waist circumference is used in conjunction with BMI to assess risk in those with a BMI of 25 to <35, but a BMI of 35 and above is considered sufficient on its own to act as a marker of disease risk (SIGN 2010).

An alternative explanation could be that participants did not know their BMI was in the obese range. This can be assessed empirically. In 2008-2011, a random sub-sample of participants was asked to assess their weight and it is evident from their answers that most people with BMI ≥30 did recognise that they were at the very least overweight: just 6% thought their weight was about right, 69% said they were overweight and 24% said very overweight.[21] We can therefore reject the idea that obesity was not reported as a health condition because people did not recognise their weight was outside the typically defined "healthy range" (BMI 18.5-<25).

Longitudinal analysis of obesity

Having looked at obesity from the perspective of participants' reported conditions, this section now looks at its association with mortality, again using the 1998 SMR-linked dataset. The following six groups were identified:

1. **One long-term condition, and BMI ≥30**
2. One long-term condition, BMI <30
3. Two or more long-term conditions, and BMI ≥30
4. Two or more long-term conditions, BMI <30
5. No long-term conditions, and BMI ≥30
6. No long-term conditions, BMI <30

As before, group 1 was of most interest, as they would be newly classified as having multiple conditions if obesity was counted as a condition. Both the Kaplan-Meier plot (Figure 5.6) and the ORs (Table 5.18) show that the risk of death was largely unaffected by people's BMI status and was instead quite closely clustered according to their condition count.

[21] These results come from the Knowledge, Attitudes and Behaviours module of the survey, unweighted sample size for the group with BMI in the obese (≥30) range: 2,160.

Figure 5.6 Kaplan-Meier plot of survival among adults aged 16-74 at baseline, for the six long-term condition and BMI status groups (14.9 years' follow-up), SHeS 1998-SMR linked data

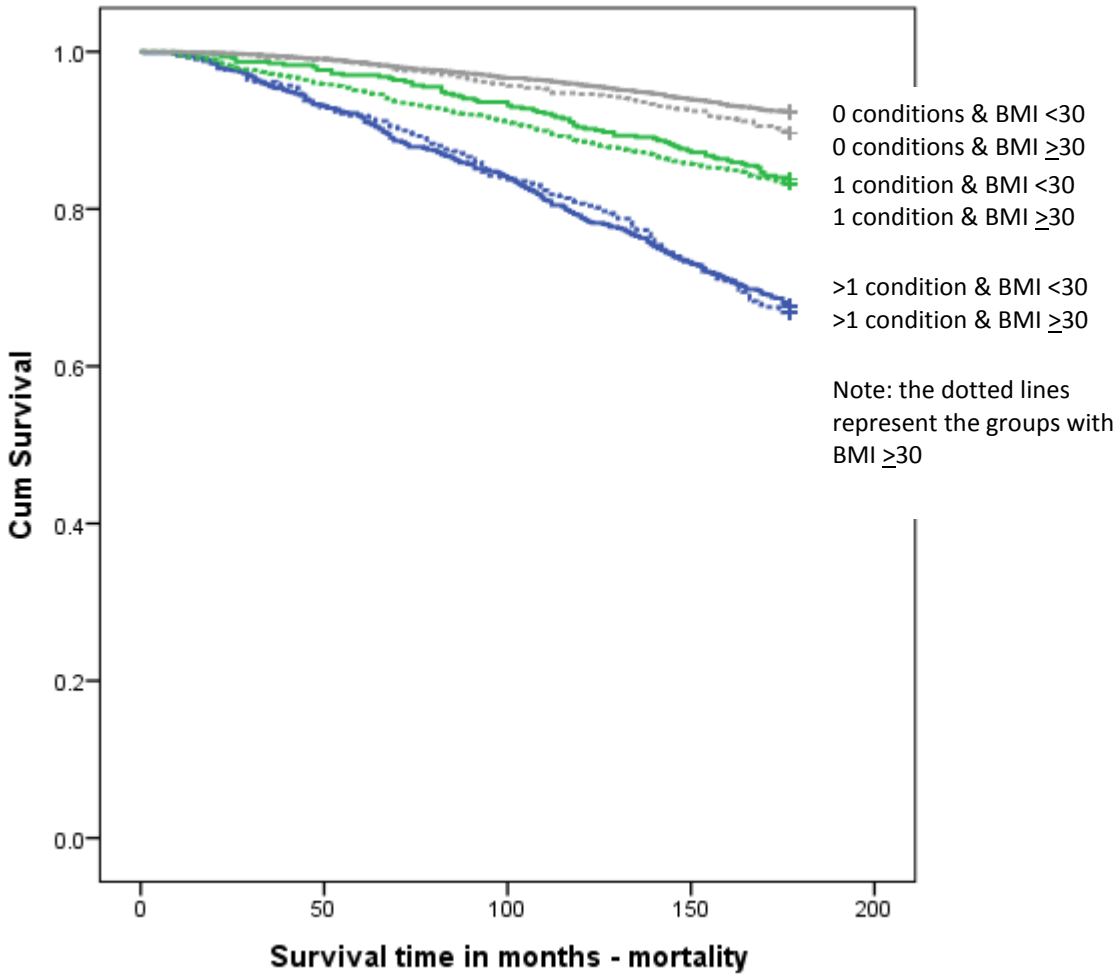


Table 5.18 Unadjusted and adjusted ORs for mortality in adults aged 16-74 at baseline, by long-term condition number and BMI status, SHeS 1998-SMR linked data

Condition / other health problem status **(reference group: no conditions, and BMI <30)**	**Unadjusted OR**	**95% CI[a]**	**Adjusted OR (sex and age)**	**95% CI[a]**
(1) One long-term condition, and BMI ≥30	**2.6**	**1.9-3.5**	**1.3**	**0.9-1.8 [n.s.]**
(2) One long-term condition, BMI <30	2.7	2.2-3.3	1.6	1.3-1.9
(3) Two or more long-term conditions, and BMI ≥30	6.8	5.2-8.9	2.3	1.7-3.1
(4) Two or more long-term conditions, BMI <30	6.5	5.2-8.1	2.7	2.1-3.4
(5) No long-term conditions, and BMI ≥30	1.4	1.0-1.8	0.9	0.7-1.3 [n.s.]

[a]p value for all CPHRs ≤0.04, unless otherwise stated.

Summary of outcome

On the basis that people did not themselves identify with obesity as something that should be characterised as a health condition or problem (note that this does not mean people thought obesity was not problematic *for their* health, it simply means they didn't classify it *as a* health problem), and it did not appear to confer any additional mortality risk over and above their underlying long-term condition count, obesity was not included in the measurement of multiple conditions in this thesis.

Mental health problems and disorders

Issues to be resolved

Two sets of measurement issues were highlighted in the case study in Chapter 4 of mental health problems and disorders. Firstly, it is known that mental health conditions attract stigma which, in the context of a face-to-face survey interview, might lead to people under-reporting such issues. Secondly, the burden of mental ill-health is under-diagnosed such that more people are estimated to live with life-impacting symptoms than ever receive a formal diagnosis of them. The survey presents a number of options for resolving these issues. Firstly, it collected information about prescription medication use (for a sub-sample of participants) which could be used to identify people taking psychoactive drugs, which could act as a proxy for having been

diagnosed with a mental health condition, even if they did not report it. Secondly, it contained a number of measures of mental health symptoms and distress which could help to identify people with diagnosed conditions (based on their symptoms), or to identify people living with symptoms but without a diagnosis. As the discussion in Chapter 4 highlighted, however, the reported symptom data is particularly problematic as it lacks sufficient contextual information to meet the diagnostic requirements that would (or should) be applied in a clinical setting.

Psychoactive prescription medication use and under-reporting of mental health conditions

The following British National Formulary (BNF) (2009) codes were used to identify people taking medications that could be considered a proxy for having received a diagnosis of a mental health condition (prevalence in brackets, N=4,273):

- 4.1.2 Benzodiazepines (anxiolytics) (0.7%)
- 4.2.1-4.2.3 Anti-psychotics and anti-manics (0.8%)
- 4.3.1-4.3.4 Anti-depressants (tricyclic, monoamine oxidase inhibitors (MAOI) & selective serotonin reuptake inhibitors (SSRI)) (8.5%)
- 4.4.0 Stimulants used in the treatment of ADHD (0.0%)
- 4.10.1-4.10.3 Drugs used in substance dependence (0.2%)

Hypnotic drugs (sleeping tablets) were also identified (1.2%), but not used as a proxy for a mental health condition diagnosis as these can often be used on a short-term basis for insomnia with no connection to a long-term psychological condition.

In total, 9.4% of adults were taking a prescription medication that potentially indicated an underlying mental health condition. Within this group (N=466), less than half (39.7%) reported a mental health condition as either a long-term condition or other health problem. This suggests that a substantial degree of condition under-reporting occurred in the survey – as illustrated by the fact that the prevalence of any mental health condition increased from 6.2% to 11.9% after the medication data had

been taken into account. This raises two important questions: how much of this discrepancy was caused by under-reporting, and, more challengingly, why did it occur?

Not all of the discrepancy will be due to under-reporting of conditions. For example, some of the people taking the older tricyclic antidepressant drugs could have been prescribed these for pain management or migraine prophylaxis (the nurses were not asked to probe this in order to identify these unlicensed uses). It is also plausible that in the intervening gap between the first interview and the nurse visit (in which the medications were recorded) some people had been newly diagnosed and prescribed their medication. Similarly, some of the discrepancy will be accounted for by people whose symptoms had reached a point (via the medication, or other mechanisms) that they no longer considered themselves to have the condition for which the drugs were originally prescribed. In which case, their lived experience and non-identification with the condition should arguably count for more than their medication use, though the illness work associated with adhering to their medications will likely still impose a burden in much the same way that taking blood pressure medication in the absence of hypertensive symptoms can. In addition, there are potential ethical issues with imputing information about conditions that participants choose not to disclose. However, it remains the case that the experiences of some people living with mental health conditions were not adequately captured by the survey's data collection method, and therefore an important aspect of their illness experience is missing. This failure of the method might have occurred due to people's unease at disclosing their condition to the interviewer, regardless of the circumstances, or in the case of interviews conducted in the presence of family members (i.e. partners, children, parents) it might have been their presence that led to the non-disclosure.

Table 5.19 below compares the age and sex profiles of people who reported a mental health condition and those who were taking psychoactive medications but had not reported a mental health condition. It also presents their levels of psychological distress (measured by GHQ12) and low wellbeing (measured by WEMWBS). Although the sample available for this analysis is small, two aspects stand out very clearly: the people with undeclared mental health conditions were notably older, and had lower

levels of poor psychosocial functioning, than the people who had reported a mental health condition. The association between age and psychosocial functioning is examined in detail in Chapter 6, so will not be commented on here. However, the older age profile of the people with undeclared conditions raises the possibility that some of the under-reporting might have been caused by generational differences in people's willingness to disclose information about mental health, as well as the possibility that some of the older people taking psychoactive medications had been prescribed them without being aware of an associated diagnosis.

Table 5.19 Sex, age group, GHQ12 score of ≥4 and low wellbeing (>1 SD below mean) among people with a reported mental health condition, and people taking psychoactive drugs with no reported mental health condition, SHeS 2008-2011 (nurse sample)

	All with a reported mental health condition	No reported mental health condition but taking psychoactive medication
Sex	**%**	**%**
Men	36.9	30.9
Women	63.1	69.1
Age group		
16-24	7.9	1.2
25-34	17.6	7.6
35-44	23.0	13.0
45-54	20.7	22.8
55-64	17.9	24.0
65-74	8.4	17.7
75+	4.5	13.8
GHQ12 score ≥4	45.8	29.3
Low wellbeing	46.5	34.8
Sample size		
Sex / age	*290*	*279*
GHQ12 / wellbeing	*279 / 275*	*262*

Note: these data are based only on people who had a nurse visit.

Using these un-reported cases to augment the definition of multiple conditions increases their overall prevalence by two percentage points, from 24.9% to 26.9% (using the definition arrived at based on the stages outlined above as the baseline). Of

those people taking psychoactive drugs but with no declared mental health condition (N=278), just over half (55.3%) already met the definition of having multiple conditions. A quarter (24.0%) had one already recorded condition so were therefore newly identified as having multiple conditions as a result of this imputation, while a fifth (20.7%) had no other reported conditions.

The number of cases in this category was too small to enable the kind of survival analysis presented above to be conducted to help the question of whether this imputation *should* take place. However, a larger issue presented itself: the availability of the prescription data. The 2008-2011 surveys only collected prescription medication data from the sub-sample of adults who had a nurse visit, so while it can be used to answer the first aim of this work to identify people with multiple conditions, the limited sample size means there is only very limited scope to extend the analysis further to investigate their lives and circumstances. Furthermore, from 2012 onwards, only very limited prescription information was collected (to identify people taking anti-hypertensive medications) so this method of imputing mental health conditions from prescription data is no longer possible in Scotland.

Psychological distress symptoms

Reported symptoms of psychological distress can sometimes be used to identify people with mental health conditions (both under-reported ones, and those without a formal diagnosis). While the information that was collected about symptoms of psychological distress avoided some of the problems associated with the stigma of disclosing such issues (the GHQ-12 questionnaire is administered via a paper self-completion while the CIS-R is conducted on a one-to-one basis by a nurse), the case study in Chapter 4 highlighted a number of problems with conflating *symptoms* of mental distress with diagnoses of mental health *disorders*. Chief among these is the absence of contextual information about possible explanations for the symptoms reported that would help to distinguish between "normal" responses to difficult life events and ones that might indicate a diagnosable disorder (while acknowledging that there are difficulties associated with the construction of psychiatric diagnoses as well).

Summary of outcome

The prescription medication data provides evidence of under-reported mental health conditions. However, its availability is limited and therefore its use would limit other analytical opportunities. In an ideal world there is an argument for carrying out the kind of imputation described above (for example, the Health Survey for England could use this approach as prescription data is collected for the majority of its participants). But in this context, while it serves as a useful illustration of a limitation of self-reported conditions, the prescription data was not used as part of the final multiple condition definition. In contrast, while the data on psychological distress symptoms was more comprehensive (for GHQ-12 at least, CISR was similarly restricted to the nurse sample), it was not sufficiently specific for the purposes of identifying people with conditions. In the analysis that follows of the lives of people with multiple conditions GHQ-12 has instead been used as an indicator of the contextual challenges people face.

Biomarkers of possible undiagnosed conditions

The biomarkers of hypertension, blood sugar (glycated haemoglobin – HbA1C) and total cholesterol collected in the nurse visit provide the final potential data source for identifying conditions from within the survey. Unlike the discussion in the preceding section, these largely serve the purpose of identifying undiagnosed conditions that participants were unaware of having, rather than conditions they had actively chosen not to disclose (though such cases are not improbable, the relative lack of stigma associated with these three particular conditions makes them less likely candidates for non-disclosure, and if they had been, they would need to be poorly controlled for this analysis to identify them). The prevalence of these potential undiagnosed conditions is shown in Table 5.20. The first point to note is that, diabetes aside, there appears to be reasonably high levels of potentially undiagnosed conditions, with 17% of the adult population without a hypertension diagnosis having elevated blood pressure, and 54% of the adult population having untreated high cholesterol. Integrating this information into the measure of multiple conditions could, therefore, have a notable impact on the overall prevalence and the composition of the group.

Table 5.20 Potential undiagnosed diabetes, hypertension, and high cholesterol in adults aged 16 and over, SHeS 2008-2011 (nurse sample)

	Men	Women	All adults
Condition	**%**	**%**	**%**
Undiagnosed diabetes: HbA1C ≥6.5% and no declared diabetes	2.6	2.1	2.4
Undiagnosed hypertension: SBP ≥140 mmHg or DBP ≥90mmHg and no declared hypertension	18.8	15.1	16.9
Undiagnosed high cholesterol: Total cholesterol ≥5.0 mmol/l and not taking lipid lowering drugs	51.9	56.2	54.1
Sample sizes:			
Diabetes	*1339*	*1669*	*3008*
Hypertension	*1575*	*2062*	*3637*
Cholesterol	*1426*	*1743*	*3169*

Note: Percentages are weighted, sample sizes are unweighted

These prevalence figures underlie one of the key objections to using this kind of information for the definition being developed in this analysis: the potential for overdiagnosis. Allocating an additional condition status to half the population in the case of high cholesterol, and nearly a fifth in the case of hypertension, on the basis of measures taken at a single point in time, clearly crosses a diagnostic boundary for which surveys are not intended. While these levels of potential undiagnosed conditions might provide useful population health data for public health policy purposes, using them to diagnose conditions at the individual level is inadvisable. Secondly, as the intended ultimate purpose of the multiple conditions measure is to try and provide contextual information about the lives of people living with multiple conditions, using information about conditions people are unaware they have is a very clear departure from the person-centred approach that has been favoured throughout.

Summary of outcome

Biomarkers provide useful information about health risks in the population but are inappropriate for the purpose of identifying people with conditions.

New definition of multiple conditions

Overview

The overall outcome of the stages presented above was the development of a new measure of multiple conditions in the population, based on the following sources of information:

- All conditions people reported when asked about long-term conditions, with no aggregation of identical codes and no grouping at the level of ICD chapters.
- Additional reports of doctor-diagnosed (and still treated / symptomatic) hypertension.
- Additional reports of doctor-diagnosed diabetes.
- Additional reports of stroke, MI and angina if they occurred within the previous 12 months.
- Other health problems, if people also reported their general health to be less than good.

The following potential sources of information were not used in the definition: BMI ≥30; psychoactive medication use; psychological distress symptoms; biomarkers of potentially undiagnosed hypertension, diabetes, and high cholesterol.

This section presents the prevalence of multiple conditions using the original and new definitions. It then compares various demographic characteristics of the group originally defined as having multiple conditions at the start of the process with the group identified by the end of it. This is further explored by looking at the characteristics of the people within the new definition based on whether their inclusion was a result of the definition change. The mortality risks associated with the two definitions are also presented. Finally, the estimates based on these definitions are compared with those derived from analyses of primary care data published in McLean et al. (2014). To aid the interpretation of proportions being compared between the different definitions and sources, 95% confidence intervals have been provided where necessary.

Prevalence of multiple conditions using the original and new definitions

Based on the new definition, 24.9% of adults aged 16 and over in Scotland had multiple conditions in the 2008-2011 period. This represents an increase of 7.7 percentage points compared with the survey's original measure of 17.2%. The breakdown of the nature of the change in overall prevalence in Table 5.21 shows that around a third of those identified as having multiple conditions were unaffected by the definition change, a third were newly identified as a result, and a further third had their number of conditions extended.

Table 5.21 Prevalence of multiple conditions in adults in Scotland, original and new definitions compared, SHeS 2008-2011

	Original	**New definition**
Number of conditions	**% (CI)**	**% (CI)**
None	57.9	51.9
	(57.2-58.7)	(51.2-52.7)
One	24.9	23.1
	(24.3-25.5)	(22.6-23.7)
Two or more	17.2	24.9
	(16.6-17.7)	(24.3-25.6)
-No change	-	*8.8 (8.5-9.3)*
-newly identified	-	*7.7 (7.4-8.1)*
-extended	-	*8.3 (8.0-8.7)*
Mean no. of conditions[a]	1.6	2.0
Standard error of mean	0.008	0.011
Median	1.0	2.0
Sample size		
All adults 16+: 28,772		
All with conditions (original): 13,155		
All with conditions (final): 15,161		

Note: Percentages are weighted, sample sizes are unweighted.
[a]Mean & median no. of conditions is based only on those with conditions.

Impact of the definition change on population sub-groups

Table 5.22 compares the age, sex, area deprivation and self-rated health profile of the group with multiple conditions, based on the original and new definitions. People aged 65 and over, and those in less than good health were, in absolute terms, the groups most affected by the change in definition (in terms of having the largest increases in the proportion identified as having multiple conditions). Men and women

were equally affected, while the percentage point difference in prevalence increased gradually as deprivation increased.

Table 5.22 Prevalence of multiple conditions by sex, age, SIMD quintile and self-rated health, original and new definitions compared, SHeS 2008-2011

		Original	New definition	Increase (p.p.)	*Sample size*
Total	%	17.2	24.9	7.7	*28,772*
Sex					
Men	%	15.3	23.0	7.7	*21,516*
Women	%	18.8	26.7	7.9	*16,256*
Age group					
16-24	%	4.0	5.4	1.4	*2,553*
25-34	%	5.7	8.5	2.8	*3,702*
35-44	%	10.3	14.1	3.8	*4,825*
45-54	%	16.3	22.8	6.5	*5,233*
55-64	%	25.6	37.0	11.4	*5,064*
65-74	%	32.2	48.4	16.2	*4,206*
75+	%	39.4	59.0	19.6	*3,789*
SIMD quintile					
5th least deprived	%	12.5	18.7	6.2	*5,079*
4th	%	14.3	20.9	6.6	*6,489*
3rd	%	17.3	25.5	8.2	*6,102*
2nd	%	19.0	27.8	8.8	*5,484*
1st most deprived	%	23.0	32.0	9.0	*5,618*
Self-rated health					
Very good / good	%	7.6	11.6	4.0	*21,105*
Fair	%	38.4	58.8	20.4	*5,323*
Bad / very bad	%	66.9	84.9	18.0	*2,339*

Note: Percentages are weighted, sample sizes are unweighted

The association between multiple conditions and deprivation is well established, particularly in Scotland (Barnett et al. 2012; McLean et al. 2014), with a key feature being the much earlier onset of conditions in people living in deprived areas. Figure 5.7 illustrates this pattern: prevalence of multiple conditions among adults aged under 65 living in the most deprived SIMD quintile reaches levels not experienced by those in the least deprived quintile areas for another 20 years. The absolute percentage point (p.p.) difference in multiple condition prevalence between the least and most deprived SIMD quintiles is also illustrated. It increases markedly from 5 p.p. for those aged 16-

34, to as much as 30 p.p. for those aged 55-64, before declining again to just over 15 p.p. in the two oldest age groups.

Figure 5.7 Prevalence of multiple conditions (new definition) in least and most deprived SIMD quintiles, and percentage-point gap size, by age group, SHeS 2008-2011

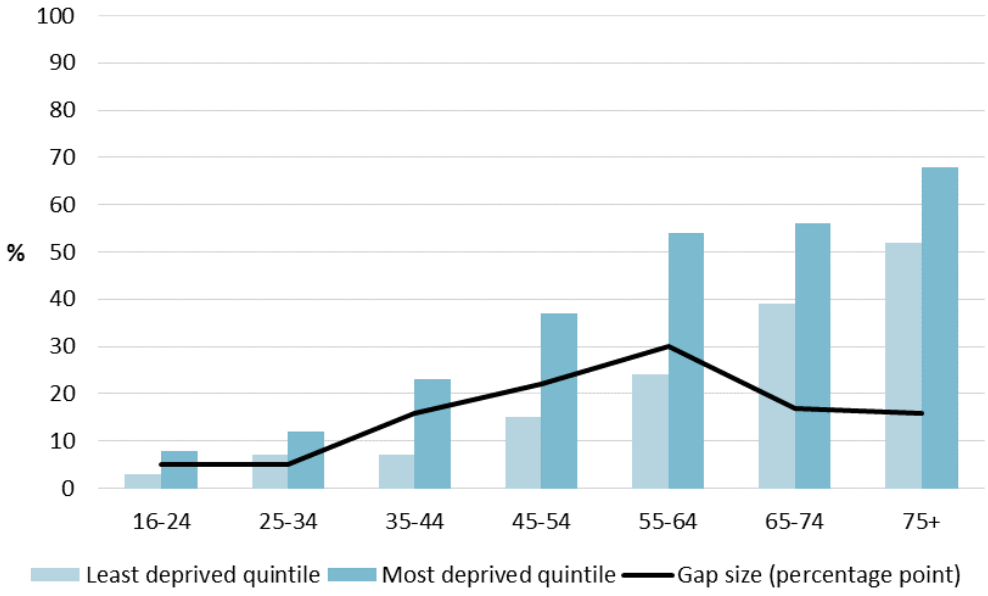
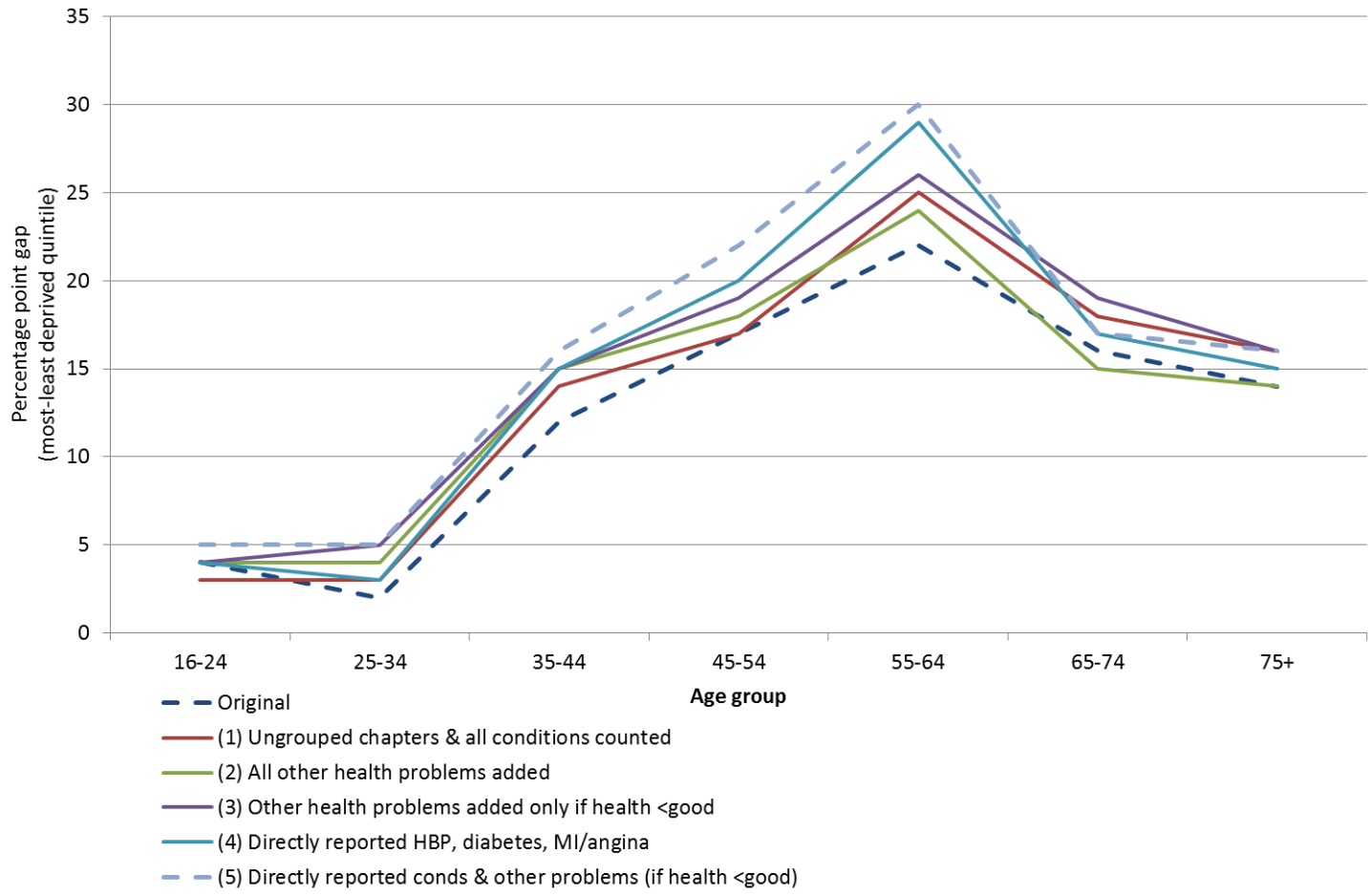


Figure 5.8 below extends this analysis and illustrates how the gap in prevalence between the least and most deprived areas varied according to the different definitions applied. When compared with the original definition, the new definition resulted in an increase in the absolute difference for all age groups, though the impact was much less notable at older ages. Most of the intervening stages also increased the gap relative to the original definition. This illustrates the extent to which the original definition was underestimating the burden of conditions among people living in deprived areas.

Figure 5.8 Percentage point difference in multiple condition prevalence between most and least deprived SIMD quintiles, by age group and definition, SHeS 2008-2011



A key concern throughout this process was to ensure that the changes to the definition did not result in making the composition of the group with multiple conditions unhelpfully diverse in terms of their overall health status. Two pieces of evidence can be presented to illustrate how the new definition managed to avoid this. Firstly, Table 5.23 compares the composition of the three sub-groups of people with multiple conditions highlighted in Table 5.21 above: those unaffected by the definition change, those newly identified as having multiple conditions, and those already identified but whose condition number was extended. The sex profile of the three groups was broadly similar, whereas the age profile of the newly identified group was more similar to the group with extended conditions than the group unaffected by the definition change. In contrast, the deprivation and health status measures were more similar for the unaffected and newly identified groups, with the extended conditions group standing out as having notably worse health, higher levels of psychological distress and more outpatient service use. The overriding point from this analysis is, however, that while the newly identified group was certainly healthier than the group whose conditions were extended, they were very similar to the group unaffected by the definition change, and hence did not constitute a group with a wholly different – healthier - profile.

Table 5.23 Multiple condition status by sex, age, SIMD quintile, self-rated health, GHQ 12, and outpatient use, SHeS 2008-2011

	Multiple condition status within the new definition		
	No change – already identified	**Condition/s added – newly identified**	**Condition/s added – newly extended**
	%	**%**	**%**
Total	**8.8**	**7.8**	**8.3**
Sex			
Men	42	47	45
Women	58	53	56
Age group			
16-34	13	8	3
35-54	32	24	21
55-74	39	46	49
75+	15	23	27
1st most deprived SIMD quintile	25	23	28
Bad / very bad self-rated health	18	17	40
GHQ12 ≥4	24	22	32
Hospital outpatient in past 12 months	54	54	65
Sample sizes			
Age, sex, SIMD	*2806*	*2565*	*2804*
GHQ12	*2522*	*2251*	*2467*
Outpatient in past 12 months	*2802*	*2560*	*2796*

Note: Percentages are weighted, sample sizes are unweighted

The second piece of evidence supporting this conclusion comes from longitudinal analysis of mortality, based on the 1998 survey. Table 5.24 presents the unadjusted and sex, age and deprivation adjusted CPHRs for mortality risk using the original and new definitions, as applied to the 1998 survey data, while Figures 5.9 and 5.10 present the survival plots.[22] The unadjusted CPHR associated with multiple conditions was higher using the new definition (5.8) compared with the original (4.9), reflecting the older profile of the new group. After adjustment, the mortality risk associated with multiple conditions was similar across the two definitions (2.1 and 2.2, respectively).

[22] The proportional hazards assumption was met for these analyses, as demonstrated by the log-log plots in Figures G2 and G3 in Appendix G.

This suggests that changing the definition did not result in creating a group with a healthier profile.

Figure 5.9 Kaplan-Meier plot of survival among adults aged 16-74, using the original definition of multiple conditions (14.9 years' follow-up), SHeS 1998-SMR linked data

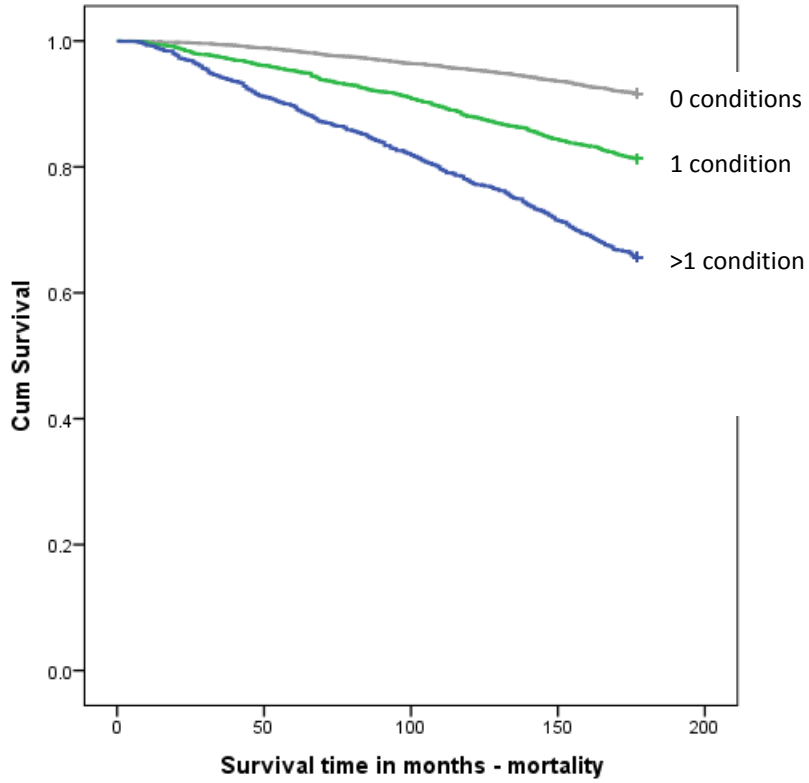


Figure 5.10 Kaplan-Meier plot of survival among adults aged 16-74, using the new definition of multiple conditions (14.9 years' follow-up), SHeS 1998-SMR linked data

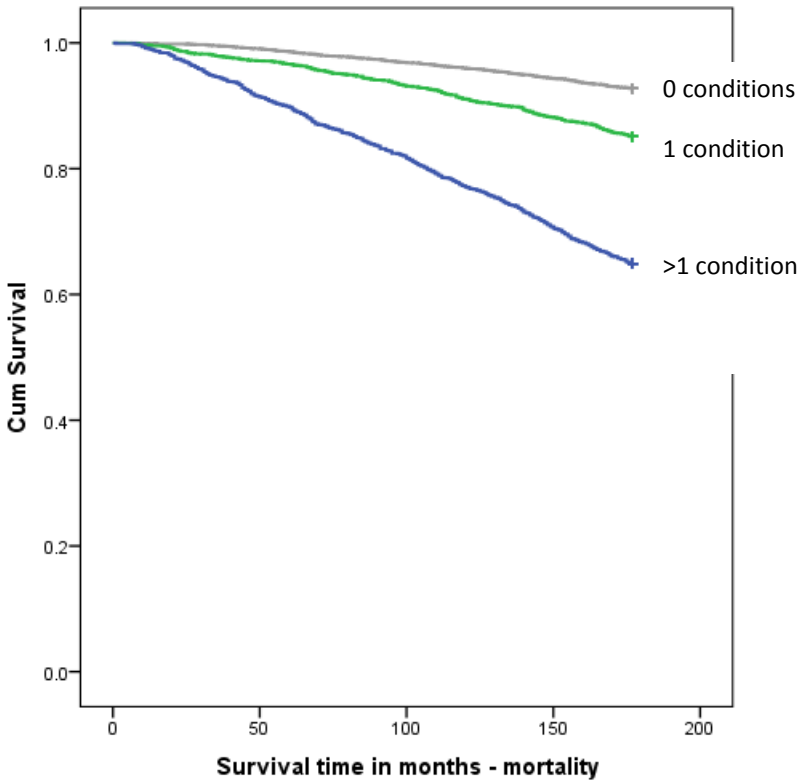


Table 5.24 CPHRs for mortality in adults aged 16-74 at baseline, by multiple conditions – original and new definitions compared, SHeS 1998-SMR linked data

Reference group: no conditions	Unadjusted CPHR	95% CI[a]	Adjusted CPHR (age, sex and deprivation[b])	95% CI[a]
Original definition				
One condition	2.4	2.1-2.7	1.5	1.3-1.7
Two or more	4.9	4.2-5.6	2.1	1.4-1.7
New definition				
One condition	2.1	1.8-2.5	1.3	1.1-1.5
Two or more	5.8	5.1-6.6	2.2	1.9-2.6

[a]p value for all CPHRs ≤0.01, unless otherwise stated.
[b]Carstairs 2001 score.

Comparison with estimates based on primary care data

As noted in Chapter 2, a database of primary care data covering around a third of Scotland's population in 2007 has been used to estimate prevalence of multiple conditions. McLean et al.'s (2014) analysis of this data source focused specifically on patterns by area deprivation in adults aged 25 and over, and provided prevalence estimates using ten-year age groups that can be easily compared with the SHeS estimates (the figures in Barnett et al. (2012) use larger age groups). There are four important points to note in Table 5.25. Firstly, the SHeS estimate based on the new definition for adults aged 25 and over (28.1%) is much closer to the primary care figure of 31.1%, than the original SHeS estimate (19.3%). Secondly, both sources had similar estimates for those aged 25-64 (no more than a 2 p.p. difference). However, the new definition still underestimates prevalence in people aged 65 and over – quite markedly – with the biggest difference between the sources as large as 17.1 p.p. (and twice this size when using the original definition). Finally, and partly explaining some of these figures, the SHeS figures overestimate the prevalence of people with one condition, relative to the primary care results, particularly for the oldest age groups. Further possible reasons for these patterns, and their implications, are discussed in Chapter 7.

Table 5.25 Prevalence of multiple and single conditions in adults aged 25 and over by age group, SHeS 2008-2011 compared with figures in McLean et al. (2014)

		SHeS 2008-2011 (original definition)	SHeS 2008-2011 (new definition)	McLean et al. 2014, Table 1 (2007 data)	Difference (SHeS new – McLean)
Multiple conditions					
Age group					
25-34	**%**	5.7	8.5	8.1	0.4
35-44	**%**	10.3	14.1	13.9	0.2
45-54	**%**	16.3	22.8	23.0	-0.2
55-64	**%**	25.6	37.0	38.9	-1.9
65-74	**%**	32.2	48.4	59.0	-10.6
75+	**%**	39.4	59.0	76.1	-17.1
Total 25+[a]	**%**	19.3	28.1	31.1	-3.0
	(CI)	(18.7-19.9)	(27.4-28.8)	(31.0-31.2)	
One condition					
Age group					
25-34	**%**	19.2	18.1	17.9	0.2
35-44	**%**	22.8	21.6	21.8	-0.2
45-54	**%**	26.1	25.4	25.0	0.4
55-64	**%**	30.4	28.4	26.5	1.9
65-74	**%**	31.0	27.8	22.6	5.2
75+	**%**	31.8	25.8	15.2	10.6
Total 25+[a]	**%**	26.2	24.2	21.9	2.3
	(CI)	(25.6-26.8)	(23.7-24.8)	(21.8-22.0)	

[a]The total figures for the McLean data were estimated from the data provided in the published table for each age group.

The above results suggest that the overall prevalence estimates in SHeS quite closely mirror those provided by analyses of primary care data, although with notable underestimates for older age groups. However, the figures presented in Table 5.26 provide some potentially worrying information about the *nature* of the information contained within the SHeS estimates. The figures are based on adults aged 25 and over with multiple conditions and show what proportion of this group had any mental health conditions. The primary care data suggest that 43.7% of people with multiple conditions have at least one mental health condition, whereas the equivalent SHeS estimate was just 16.4%. Prevalence of mental health conditions declined with age in both sources, with an almost identically-sized absolute gap between the youngest and oldest groups. The level of underestimation within each age group was also fairly similar (around 25 to 32 p.p.). The concerns raised about the under-reporting of

mental health conditions discussed above are clearly evidenced here. Potential causes of this, and their broader implications, are discussed in Chapter 7.

Table 5.26 Proportion of multiple conditions which include a mental health diagnosis in adults aged 25 and over with multiple conditions, SHeS 2008-2011 compared with figures in McLean et al. (2014)

Mental only or mixed physical-mental as % of all those with multiple conditions		SHeS 2008-2011 (new definition)	McLean et al. 2014, Table 2 (2007 data)	Difference (p.p.) SHeS new – McLean
Age group				
25-34	**%**	40.3	72.7	-32.4
35-44	**%**	36.5	66.0	-29.5
45-54	**%**	26.8	54.4	-27.6
55-64	**%**	15.8	41.7	-25.9
65-74	**%**	6.3	31.7	-25.4
75 and over	**%**	4.1	36.3	-32.2
Total 25+	**%**	16.4	43.7	-27.3
Difference (p.p.) 25-34 - 75 and over		36.2	36.4	

[a]The total figures for the McLean data were estimated from the data provided in the published table for each age group.

Conclusion

The findings presented in this chapter illustrated the processes through which the new definition of multiple conditions was developed, as well as some of the implications for the prevalence and social patterning of multiple conditions that arose from the changes made. The theoretical perspectives outlined in Chapter 4, and the additional empirical information outlined here, were brought together to help determine what should and should not be included in the multiple conditions definition. This form of methodological triangulation reflected the wider aim to bring together different perspectives on people's health conditions in an attempt to capture a more rounded picture of their experiences. The resulting definition was, however, something of a bricolage, drawing on the information to hand, rather than being able to augment this with any newly collected data. It therefore exposed a number of potential problems with the conditions data, as originally collected, and as subsequently processed; these are considered in more detail in the discussion in Chapter 7. Recommendations for how these problems might be resolved, either via changes to the way the questions are

asked, or changes to the way the data are used, are also provided in Chapter 7. Before these aspects are pursued, however, Chapter 6 takes this new definition and uses it to explore the wider life experiences of people with multiple conditions, principally through the lens of their psychological wellbeing. In doing so, it attempts to not only explore how multiple conditions are associated with other outcomes, but also to reflect on the wider utility of this conceptualisation of health as a collective status.

Chapter 6 Living with multiple conditions

Introduction

Chapter 5 described the process used to arrive at a definition of people with multiple conditions, and illustrated the impact that decisions about its definition had on prevalence estimates and the composition of the group. This chapter takes this definition and uses it to explore aspects of the day-to-day experiences of people with multiple conditions, primarily using measures of psychological wellbeing. Before considering the detailed wellbeing results, there is a brief overview of some other aspects of people's lives that are known to impact on, and be impacted by, health status which is intended to help contextualise the wellbeing analysis. The wellbeing results are then presented in three stages. Firstly, the association between the survey's individual measures of wellbeing and condition status is explored using the summary measure introduced in Chapter 5 (no conditions, one condition and two or more). An extended and more finely grained measure of conditions is also used to illustrate the extent to which each additional condition is associated with outcomes (distinguishing between those with one, two, three, four and five or more conditions). Secondly, variations in wellbeing by conditions are explored by age group, area deprivation, and condition severity, with these factors explored both individually and collectively. Finally, the analysis explores some potential mechanisms that might help to account for the observed variations in wellbeing.

Throughout these stages, careful attention is paid to the question of whether the experiences of people with multiple conditions are distinctive when compared with people with one or no conditions - either in terms of their overall *level* of wellbeing, or in the *ways* in which any variations in aspects of their wellbeing manifest. In addition, where patterns emerge that appear to be distinctive of people with multiple conditions, further consideration is paid to whether further sub-groups can be identified whose experiences stand-out from their counterparts.

The previous chapter was focused on bringing together people with multiple conditions under one definition, with particular attention paid to avoiding making the group more heterogeneous in terms of their health status and mortality risk than was

the case with the original definition. In contrast, this chapter aims to explore the extent to which the experiences of people with multiple conditions can be highly heterogeneous and, most critically, socially stratified. As described in Chapter 2, much is already known about the association between condition numbers and outcomes such as psycho-social functioning. While the approach followed here replicates many of these analyses, it does so with the intention of using the insights gained to spur further thinking about their underlying mechanisms, and what they mean for the construction of categories such as "people with multiple conditions".

Selection of outcomes and rationale for analysis approach

Just as the definition decisions taken in Chapter 5 were informed by theoretically-grounded insights, the selection of outcomes and analysis approach chosen for this chapter was similarly guided. The intention is to provide more detailed insights about the lives of people living with multiple conditions, beyond the descriptive socio-demographic analyses (of age, sex and deprivation status) presented in the previous chapter (and in the wider literature). The survey's positive wellbeing instrument – WEMWBS - was selected for this purpose. The individual items within WEMWBS span a number of important functions central to people's daily lives, many of which reflect the kinds of challenges highlighted in the illness experiences literature discussed in Chapter 4. Impairments in any one of these functions can be indicative of specific problems people face, while the cumulative experience of multiple functional impairments signifies a burden that is likely to have significant consequences for people's quality of life.

These data are cross-sectional so the identification of negative (or positive) associations between wellbeing and condition numbers cannot be used to draw conclusions about causation. However, uncovering the extent to which living with multiple conditions coincides with low wellbeing provides insights into the wider experiences and challenges that this group faces. Whether their experiences are a unique feature of their condition status is an additional important issue to consider because it might help to shape further thinking about the potential mechanisms operating between these sets of outcomes. In addition to this, however, and perhaps more challengingly,

their distinctiveness – or lack thereof – opens up questions about the utility of creating groupings of people based solely on their condition numbers and effectively assigning them a singular status.

Epidemiological analysis is often concerned with ensuring that any demonstrated associations between risks and outcomes are, as far as is possible, not simply artefacts of confounding by other related factors, such as age and socio-economic status. Wellbeing has well established associations with both of these factors; however, the decision to illustrate the social stratification of these outcomes by condition number was guided by a concern to highlight these as important contextual factors, and not to treat them simply as measures whose effects need to be "controlled" for. As Charmaz (2010) points out, it is important that analyses of chronic illness experiences address contextual aspects such as these, rather than just emphasising "*the relative intrusiveness of illness and effects on identity*" (Charmaz 2010, p.8). In addition, the concern to highlight the heterogeneity of experiences among people with multiple conditions was influenced by Lofters & O'Campo's (2012) discussion of the dangers of essentialism, that is, treating a socially defined group as if it had fixed characteristics and ignoring the sub-groups and associated dynamics that exist within it.

Overview of measures

Chapters 4 and 5 contained discussion of the role of symptom-based measures of psychological distress in identifying potentially under-reported or undiagnosed disorders in the general population. For the reasons outlined there, the main psychological distress measure contained in the survey – the GHQ12 – was not used to identify conditions by proxy. It is not the main focus of this chapter, either. However, it has been used below in the introduction to wellbeing, and later on in the chapter in the analysis looking at the impact of psychological distress in conjunction with multiple conditions on mortality. GHQ12 scores of 4 or more are generally used as a marker of a potential medically diagnosable psychological disorder, so this threshold is used here. However, as noted in Chapters 4 and 5, the absence of wider contextual information on people's circumstances makes it a problematic measure of diagnosable disorders, so it has been conceptualised here to instead signal the presence of a level of

distress likely to be significantly burdensome to the person experiencing it, while remaining neutral on the question of whether they have a diagnosable condition.

WEMWBS was selected because of its potential to provide a broader level of information about people's social and psychological functioning, beyond the somewhat more symptom-focussed indicators of distress contained in the GHQ12 (for example, all WEMWBS questions are positively worded). WEMWBS is usually reported as an overall mean score (it was developed in Scotland and designed to yield a mean of 50.0 in the adult population). WEMWBS is not designed to be used to identify specific thresholds indicating particular levels of wellbeing. However, scores of more than one standard deviation below and above the mean have been used to identify people with very low and high levels of wellbeing, respectively (see, for example, Stewart-Brown et al. 2015). This is the approach adopted here. However, the 14 item scale has been shown to have measurement problems, for example, when scaled, the 14 items do not collectively represent a single underlying dimension (Stewart-Brown et al. 2009). Principal components factor analysis of this dataset confirmed this finding (results not shown). In addition, Stewart-Brown et al. (2009) showed that a number of the items displayed differential item functioning (DIF), by age and gender – but not by long-term illness – which meant that men and women, and people of different age groups, with the *same level of wellbeing* give different responses to items, which introduces measurement bias. The important point is that DIF analysis is not designed to identify differences between men and women's responses (which would be expected), but to identify where men and women with the same level of functioning give different answers to items. To address this, Stewart-Brown et al. (2009) identified a shorter, seven-item scale (short WEMWBS), that did not have these problems, and which represented a unidimensional construct, largely focusing on functioning (again, the unidimensional structure of the alternative scale was confirmed in this dataset, results not shown). For this reason, the analysis of summary wellbeing in this chapter uses the short WEWMBS measure, called SWEMWBS hereafter (the full scale is presented in Appendix E).

These summary measures are helpful ways of describing population patterns, and facilitate making comparisons across sub-groups; however, their individual components are also valuable sources of contextual information about people's lives and the kinds of difficulties they face. This chapter therefore presents the responses to the individual items (see Tables 6.1 and 6.2 below) before going on to focus on the summary measures. As noted in the introduction, however, it starts by contextualising the experience of low wellbeing by comparing it to other challenges and risks people face.

Wellbeing in context

One of the main advantages of population health surveys (such as SHeS) is the breadth of additional information they provide about people's lives that is generally absent from clinical sources, such as GP records. Much of the contextual information reported in epidemiological studies centres on factors that have a negative impact on health, or which poor health itself contributes to, such as smoking, poor diet, high BMI or low activity levels. To help place this discussion of wellbeing into the broader context of people's lives, this section briefly presents the association between condition numbers and a selection of such challenges, stratified by area deprivation, before doing the same for low wellbeing (>1 SD below the mean) and high psychological distress (GHQ12 $\geq$4). The selected aspects are:

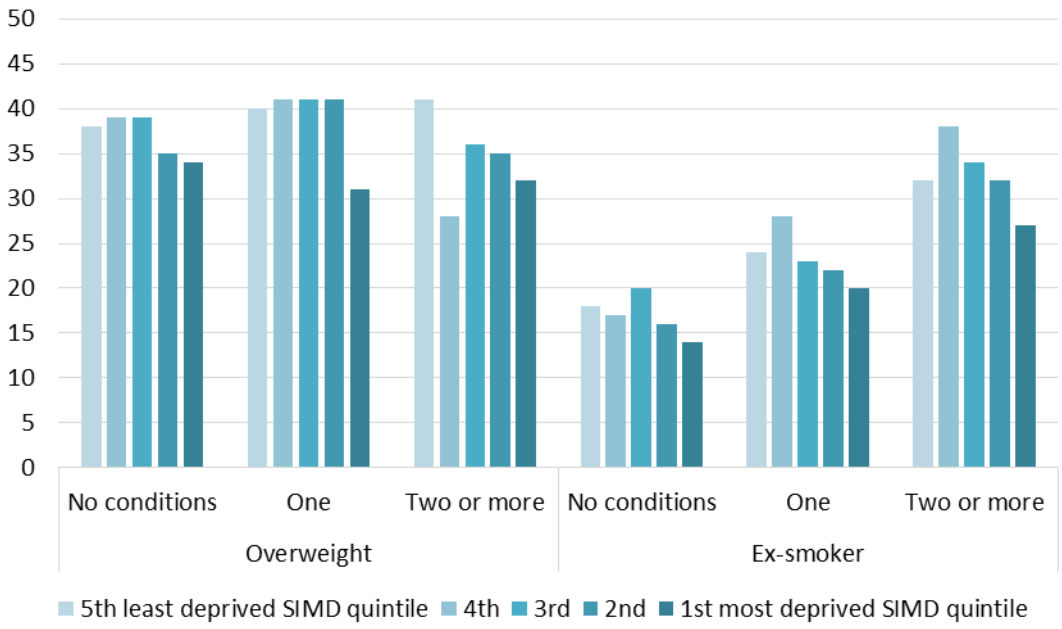
- Being a current or ex-smoker;
- Having a BMI in the overweight, or the obese, range;
- Eating fewer than two daily portions of fruit and vegetables;
- Being physically active for fewer than 30 minutes per week.

Rather than framing these as "behavioural" or "lifestyle" risks, they are presented here as examples of health "challenges" in an attempt to reflect the fact that while they capture aspects of people's lives that have been measured at the individual level, they are also markers of much more distal, sometimes historic, and often multi-layered, risks and challenges. For example, some confer specific health consequences, such as the illnesses or symptom exacerbations linked to smoking (either now or in the past); others bring social stigma or attract a level of blame that can, in clinical settings,

negatively affect the treatment people receive or the way it is delivered (e.g. high BMI, current or past smoking). Others are markers of limitations on people's personal opportunities (e.g. very low activity levels as a consequence of poor health); or reflect structural constraints, such as those imposed by income or availability on food choices.

The challenges have been grouped to illustrate four distinct patterns that are identifiable. The first pattern, in Figure 6.1, reflects challenges (being overweight or an ex-smoker) that follow a gradient such that people in more deprived areas are at lower risk, though not consistently or markedly so. A BMI in the overweight range does not appear to be strongly related to condition numbers, whereas being an ex-smoker is highest among those with multiple conditions. This latter pattern will, of course, be additionally confounded by the different age profiles of the three condition groups, and historic patterns in the prevalence of smoking. The reason for the lower prevalence of both these challenges among the most deprived areas is explained, in part, by the patterns in current smoking and obesity shown below.

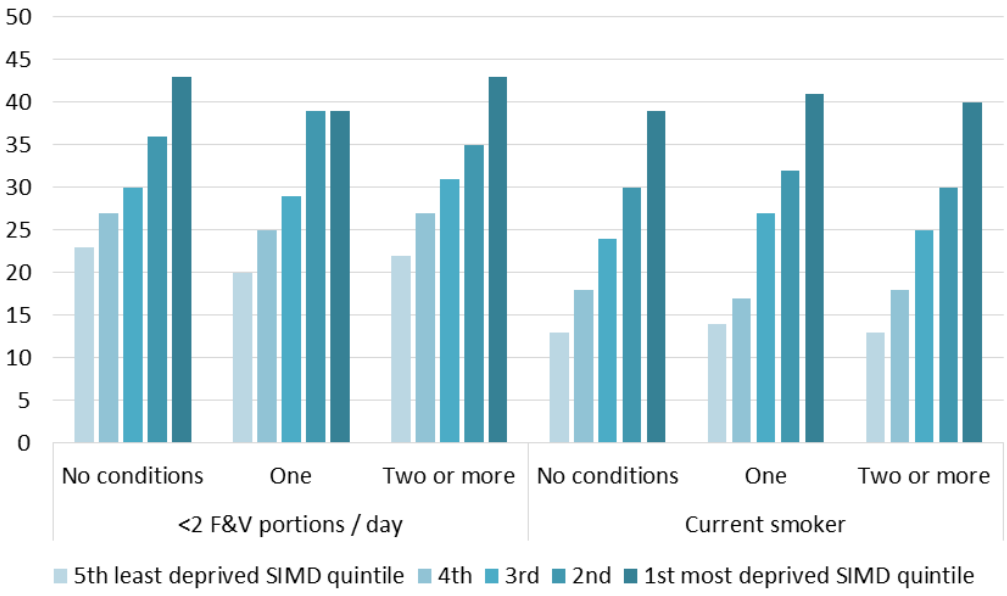
Figure 6.1 Prevalence of a BMI in the overweight range, and prevalence of being an ex-smoker, by condition number (0, 1, 2 or more) and SIMD quintile, SHeS 2008-2011



The second pattern shows that having a poor diet or being a current cigarette smoker are strongly related to area deprivation, but not to condition number. While at least

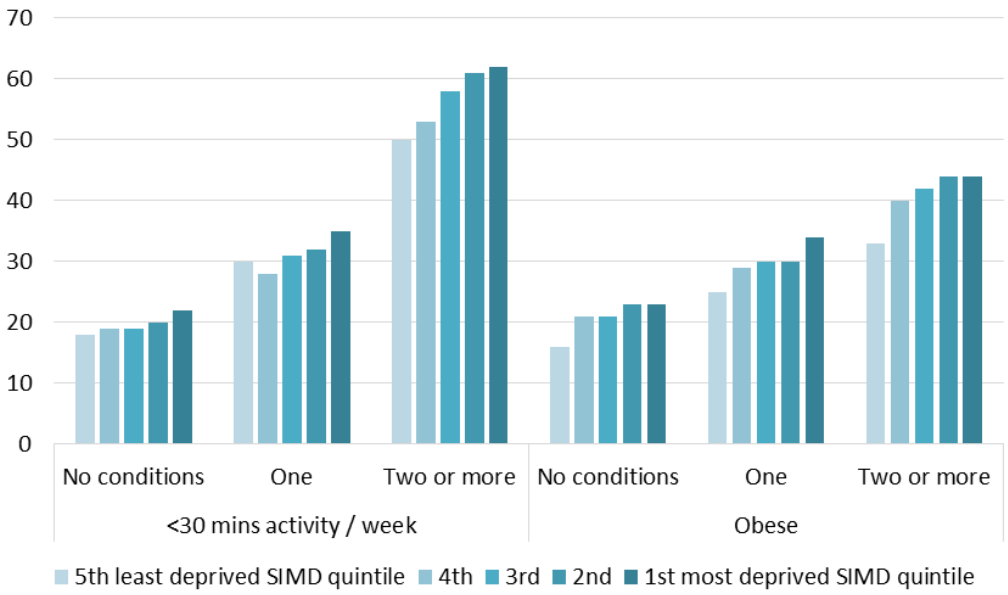
40% of people with multiple conditions living in the most deprived SIMD quintile face these considerable challenges, the same is also true for people with one or no conditions.

Figure 6.2 Prevalence of eating <2 portions of fruit and vegetables per day, and prevalence of current smoking, by condition number (0, 1, 2 or more) and SIMD quintile, SHeS 2008-2011



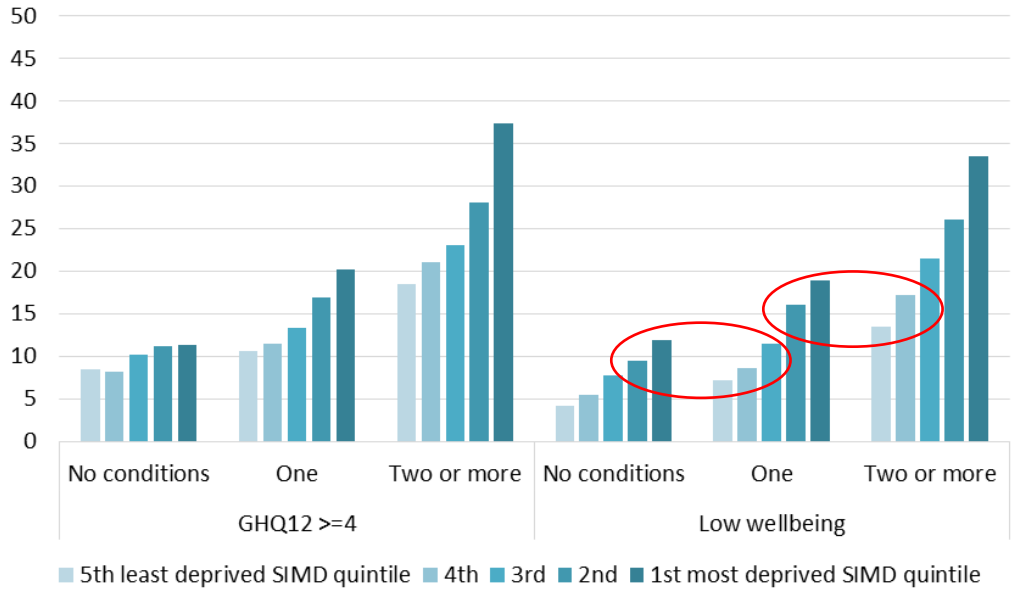
The next pattern is different again. Figure 6.3 shows that prevalence of having a BMI in the obese range, and of low activity levels, increases in a linear fashion with increasing deprivation, and with increasing condition numbers. The gradients follow a largely stepwise increasing pattern, running from those with no conditions in the least deprived areas through to those with multiple conditions in the most deprived areas.

Figure 6.3 Prevalence of being active for <30 minutes per week, and prevalence of a BMI in the obese range, by condition number (0, 1, 2 or more) and SIMD quintile, SHeS 2008-2011



The final pattern, displayed by the measures of distress and low wellbeing in Figure 6.4, is quite distinct. Here the increase in prevalence with deprivation and condition number is curvilinear, and is particularly so for low wellbeing. The increase in low wellbeing with condition number is mediated by deprivation, with the result that people living in the least deprived areas have better outcomes than those in the most deprived areas, even if they have a higher condition burden (as highlighted by the circles in the chart). This contrasts sharply with the pattern for low activity in Figure 6.3, where outcomes were always progressively worse for people within each SIMD quintile as condition numbers increased. In both sets of patterns, however, the worst outcomes of all are experienced by people with multiple conditions living in the most deprived areas.

Figure 6.4 Prevalence of GHQ12 score ≥4 and low wellbeing (SWEWMBS >1 SD below mean), by condition number (0, 1, 2 or more) and SIMD quintile, SHeS 2008-2011



The relative strengths of the association between these factors and the likelihood of having multiple conditions are illustrated by the odds ratios presented below in Figures 6.5 (for men) and 6.6 (for women), after adjusting for age and SIMD.[23] With the exception of overweight in men, they all conferred a significantly increased risk of having multiple conditions. However, the effect sizes for smoking, overweight (in women) and poor diet were fairly small, and could be the result of residual unmeasured factors. In contrast, low wellbeing stands out, having the highest odds ratios (4.2 for men and 3.5 for women) of all the challenges presented.

[23] The selection of these measures, and the manner of their presentation, was deliberately modelled on the approach in Fortin et al. (2014).

Figure 6.5 Forest plot of risks associated with having multiple conditions (2 or more versus 0 or 1) in men, adjusted for age and SIMD, SHeS 2008-2011

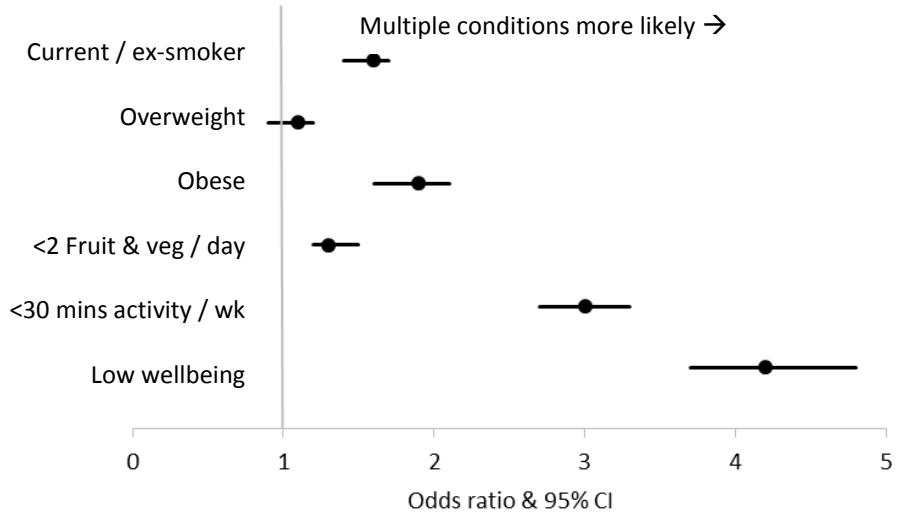
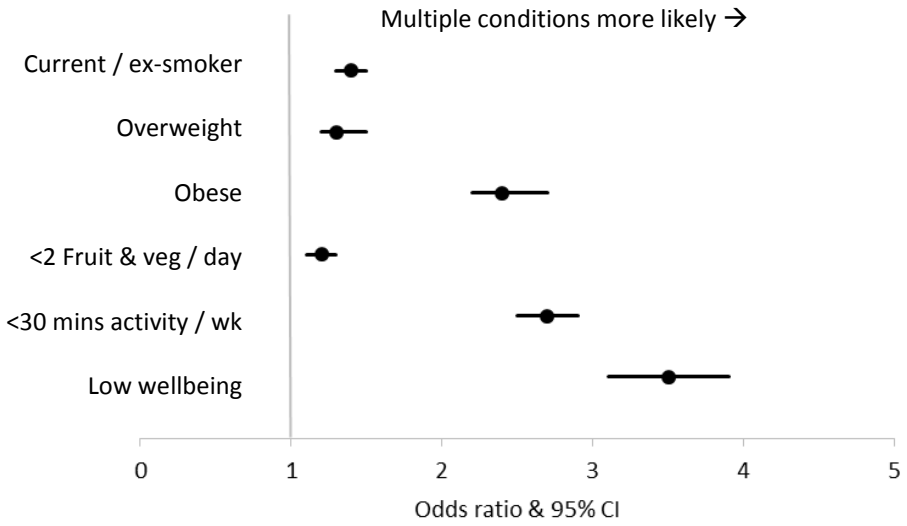


Figure 6.6 Forest plot of risks associated with having multiple conditions (2 or more versus 0 or 1) in women, adjusted for age and SIMD, SHeS 2008-2011



Having demonstrated how low wellbeing is placed in relation to other challenges people with multiple conditions experience, both in terms of the nature of its social patterning and how it contributes to the overall risk of having multiple conditions, the rest of this chapter now focuses on patterns in low wellbeing and attempts to understand some of the mechanisms behind them.

Individual indicators of low wellbeing

Table 6.1 presents the prevalence of responses to the individual WEMWBS items that indicate low wellbeing (the negative responses) so that these experiences are not completely lost in the analytic process (the items are presented in descending order of prevalence among those with multiple conditions). The analysis of outcomes presented in the rest of the chapter is based on the seven item summary SWEMWBS measure, whose items are indicated with asterisks in Table 6.1 and Figure 6.7. Figure 6.7 supplements Table 6.1 by showing the prevalence of negative responses for each scale item using a finer breakdown of the number of conditions (0-5 or more).

Both sets of results show that responses indicating low wellbeing are far higher among people with multiple conditions than those with just one or no conditions, while the results in Figure 6.7 show how low wellbeing becomes increasingly more common as the number of conditions increases to as many as five or more (though a couple of the lower prevalence indicators show some degree of plateauing). The most commonly reported indicator of low wellbeing - having spare energy rarely or none of the time – was reported by 27.1% of all adults (this item was included in the scale as a measure of personal functioning). Of all the aspects covered in the scale, this item was a notable outlier among adults with multiple conditions, almost half of whom (47.6%) reported this, and which represented a 30 percentage point (p.p.) absolute difference compared with those with no conditions (17.7%). In contrast, the equivalent absolute differences between these two groups for the remaining scale items were much smaller (ranging from 6-14 p.p.). The results in Figure 6.7 are even more striking – over 60% of those with four conditions, and 70% of those with five or more reported having little energy. This is completely understandable, given the energy-consuming or draining nature of many of the conditions that people will have, and the fact that this is often a symptom that accompanies or signals depression. This item therefore has the potential to reveal insights about the experiences of people with multiple conditions over and above the information provided by the other individual items and illustrates the value of considering individual indicators as well as overall summary measures when trying to understand something of the lives of people with multiple health conditions.

The next two most commonly reported indicators of low wellbeing (having little optimism about the future or interest in new things) were also notable for their high prevalence among adults with multiple conditions, though even among those with the highest number of conditions the proportion reporting these two items was half that seen for having little energy. These items were intended to measure different dimensions of wellbeing (positive affect and personal development, respectively), but they are also both symptomatic of depression. They certainly highlight the extent to which people living with significant health burdens have constrained hopes about, and interest in, their future prospects.

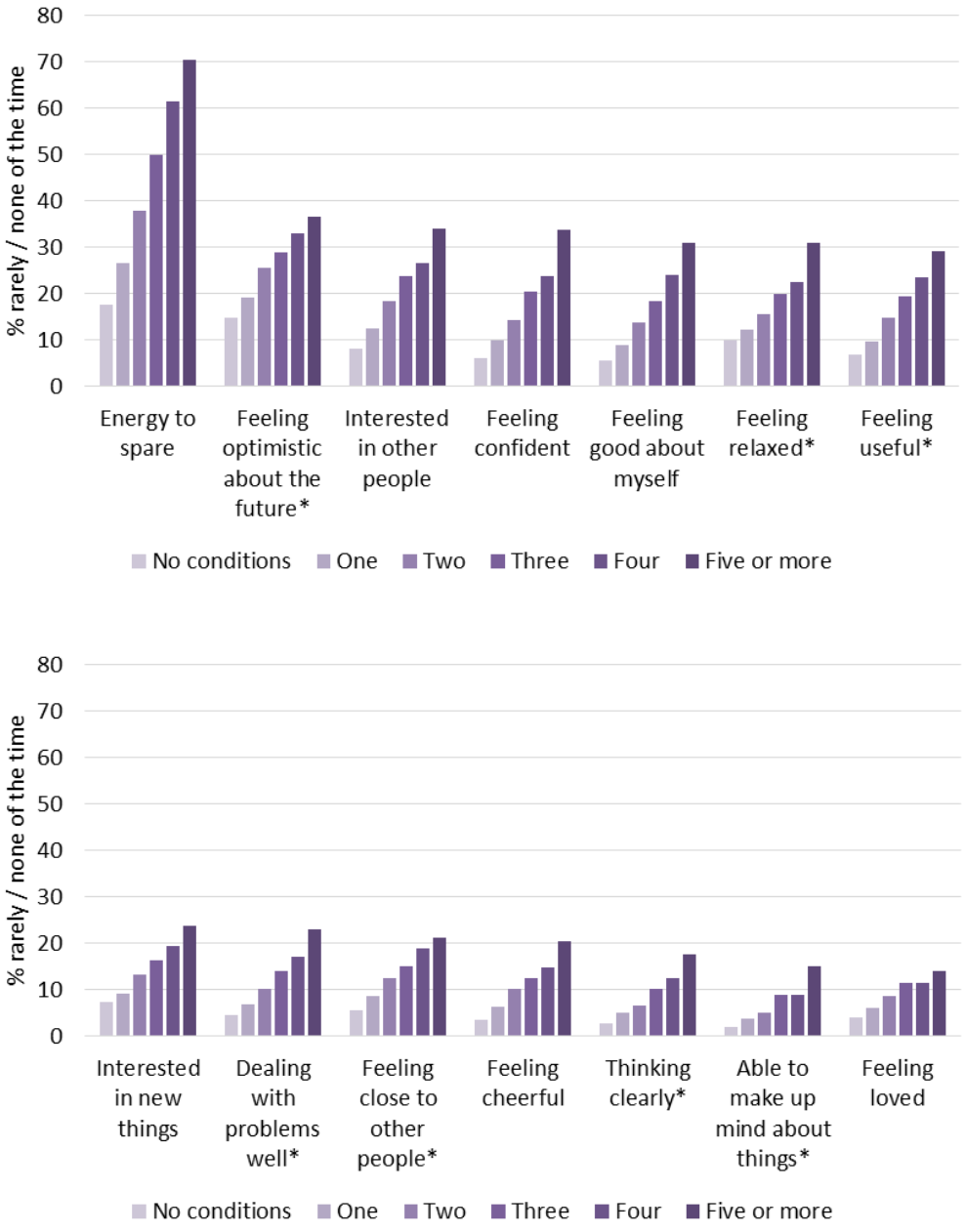
Differences in wellbeing between men and women were generally small, and where differences were evident, there was no consistent pattern. For example, men were more likely than women to say they had little interest in other people, whereas women were more likely than men to say they had been lacking confidence.

Table 6.1 Individual WEMWBS items by number of conditions (0, 1, 2 or more) and sex, SHeS 2008-2011

	Number of conditions			
WEMWBS items "rarely / none of the time" responses	**None**	**One**	**Two or more**	**Total**
	%	**%**	**%**	**%**
Men				
Energy to spare	14.0	23.8	46.3	23.6
Feeling optimistic about the future*	16.2	21.0	30.5	20.6
Interested in new things	8.2	13.1	24.1	12.9
Feeling relaxed*	8.7	10.9	17.9	11.3
Feeling useful*	6.6	9.2	19.6	10.1
Feeling confident	4.3	7.8	16.7	7.9
Interested in other people	8.5	11.5	19.4	11.7
Feeling good about myself	4.3	7.1	16.6	7.8
Feeling close to other people*	6.3	10.1	17.2	9.6
Dealing with problems well*	4.5	6.0	13.8	6.9
Feeling cheerful	4.0	6.2	12.6	6.5
Feeling loved	4.5	6.7	11.2	6.5
Thinking clearly*	2.5	4.7	9.5	4.6
Able to make up own mind about things*	2.0	3.1	6.9	3.4
Women				
Energy to spare	21.4	29.1	48.6	30.3
Feeling optimistic about the future*	13.2	17.5	27.1	17.8
Interested in new things	8.2	12.0	21.4	12.5
Feeling relaxed*	10.8	13.5	20.3	13.9
Feeling useful*	7.1	10.0	17.9	10.6
Feeling confident	7.9	12.0	21.1	12.3
Interested in other people	6.4	7.2	13.3	8.4
Feeling good about myself	6.6	10.6	19.4	10.9
Feeling close to other people*	4.8	7.0	13.2	7.5
Dealing with problems well*	4.5	7.6	13.3	7.5
Feeling cheerful	3.3	6.6	12.4	6.4
Feeling loved	3.3	5.6	9.5	5.5
Thinking clearly*	2.7	5.2	9.3	5.0
Able to make up own mind about things*	2.1	4.3	8.2	4.2
Sample sizes				
Men	*5520*	*2794*	*3135*	*11,449*
Women	*7150*	*3650*	*4240*	*15,040*

Notes:
Percentages are weighted, sample sizes are unweighted;
Sample sizes vary for each item, figures shown are the lowest of the range;
Short WEMWBS items are marked with asterisks (*).

Figure 6.7 Individual WEMWBS items by number of conditions (0-5 or more), SHeS 2008-2011

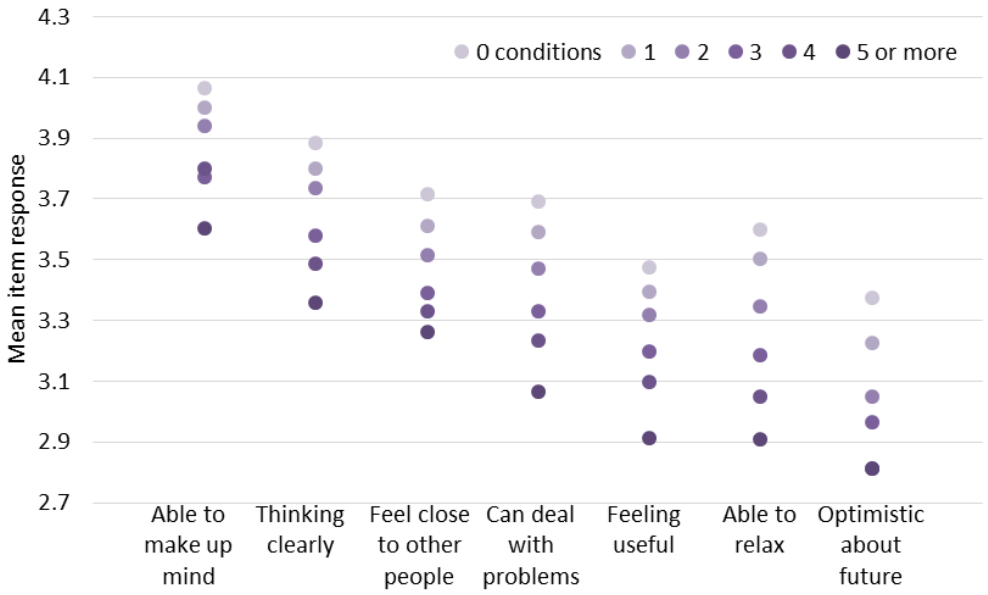


Note: *short WEWMBS items

The final results presented here compare the mean scores for each SWEMWBS scale item by condition number, using the extended measure (in Figure 6.8) and the summary measure (in Figure 6.9). It is clear from the charts above, and from Figure 6.8, that in many instances, the experiences of people with two conditions are closer to

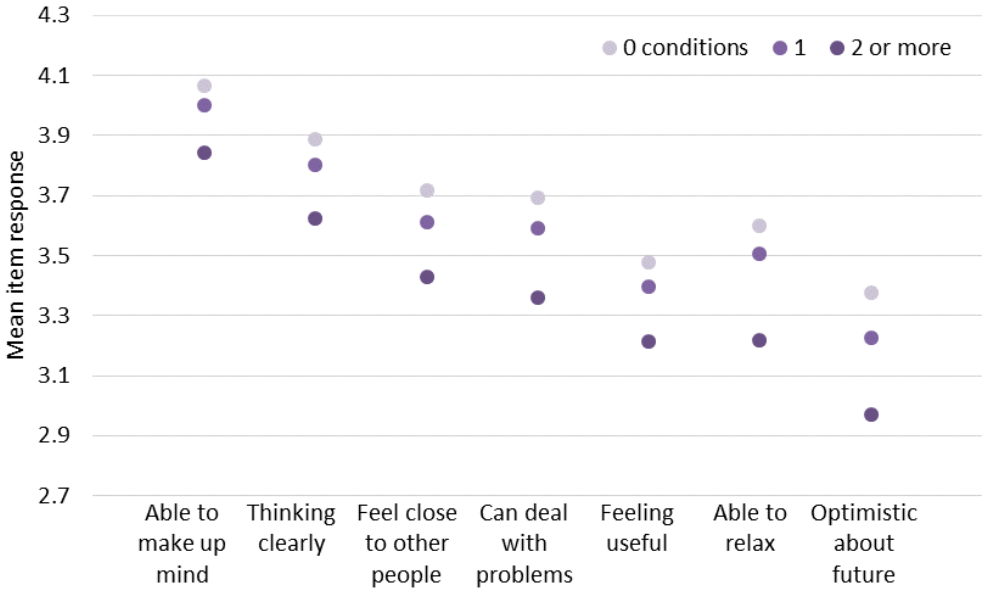
those reported by people with one condition rather than those with three, and are certainly very distinct from the experiences reported by people with the highest condition burdens. Indeed, no clear threshold presents itself as demonstrating a consistent point beyond which experiences differ markedly. Consequently, although Figure 6.9 shows that collectively the experiences of people with two or more conditions are notably different – in terms of their overall levels of impaired functioning – when compared with people with one or no conditions, the two conditions or more threshold is largely arbitrary when viewed purely empirically (for this particular outcome at least).

Figure 6.8 Individual SWEMWBS item mean scores by number of conditions (0-5 or more), SHeS 2008-2011



Note: scale has been truncated for clarity, items were scored from 1-5

Figure 6.9 Individual SWEMWBS item mean scores by number of conditions (0, 1, 2 or more), SHeS 2008-2011



Note: scale has been truncated for clarity, items were scored from 1-5

Variations in summary wellbeing

Condition number

Having considered the individual aspects covered by WEMWBS/SWEMWBS, Table 6.2 and Figure 6.10 now present the SWEMWBS mean and median scores, and the percentage with low wellbeing (scores >1 SD below the mean). For comparison, the percentage with high wellbeing (>1 SD above the mean) is also shown.

Mean SWEMWBS scores showed a statistically significant (though not necessarily substantively significant) decline from 25.9 for those with no conditions, to 25.2 for those with one, and to 23.7 for those with multiple conditions. Similarly, the prevalence of low wellbeing trebled between the group with no conditions (6.5%) and the group with multiple conditions (23.1%). In contrast, high wellbeing was only very weakly associated with condition numbers, with the difference between groups relatively small (14.0% for those with no conditions, 10.0% for those with two or more). The different patterns found for men and women's individual wellbeing indicators balanced out across the whole population such that mean scores were

identical for men and women with multiple conditions, and levels of low or high wellbeing were also similar.

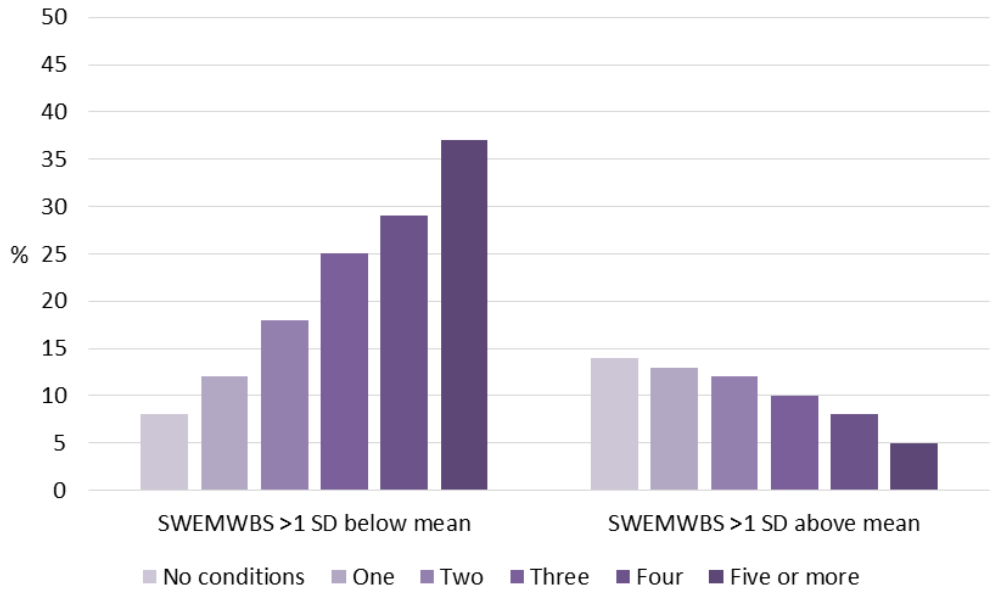
Table 6.2 SWEMWBS summary measures by number of conditions and sex, SHeS 2008-2011

	Number of conditions			
	None	**One**	**Two or more**	**Total**
	%	**%**	**%**	**%**
Men				
Mean score	25.9	25.2	23.7	25.3
Standard deviation	3.7	4.2	4.8	4.2
Standard error	0.05	0.08	0.09	0.04
>1 SD below mean (%)	6.5	11.5	23.1	11.4
>1 SD above mean (%)	14.7	13.4	10.3	13.4
Women				
Mean score	25.7	25.0	23.6	25.0
Standard deviation	3.8	4.3	4.7	4.3
Standard error	0.05	0.08	0.08	0.04
>1 SD below mean (%)	8.4	12.7	23.9	13.4
>1 SD above mean (%)	13.4	13.0	9.7	12.4
All adults				
Mean score	25.8	25.1	23.7	25.1
Standard deviation	3.8	4.3	4.8	4.2
Standard error	0.03	0.05	0.06	0.03
>1 SD below mean (%)	7.5	12.1	23.5	12.5
>1 SD above mean (%)	14.0	13.2	10.0	12.9
Sample sizes				
Men	*5487*	*2762*	*3096*	*11,345*
Women	*7084*	*3618*	*4186*	*14,888*
All adults	*12,571*	*6380*	*7282*	*26,233*

Note: Percentages are weighted, sample sizes are unweighted.

Figure 6.10 shows that both measures increased with increasing numbers of conditions to the point where over a third of people with five or more conditions had a SWEMWBS score >1 SD below the mean. In contrast, there was considerably less variation in scores >1 SD above the mean, with only very small declines as condition numbers increased. Clearly, an absence of conditions does not equate to very high levels of wellbeing in the same way that the presence of multiple conditions is accompanied by low levels of wellbeing. High wellbeing prevalence is not explored any further in this chapter.

Figure 6.10 Prevalence of SWEMWBS >1 SD below mean, and >1 SD above mean, by condition number (0-5 or more), SHeS 2008-2011



Condition number and age group

The headline figures reported in the previous section are now explored further to illustrate the way in which wellbeing differs quite markedly across the generations, and interacts with the number of conditions people have. Figure 6.11 shows that within each age group, low levels of wellbeing increase with the number of conditions reported, and those with multiple conditions always have the highest burden. But when the age groups are compared, it is clear that the absolute burden of low wellbeing is greatest for those with multiple conditions aged 16-64, while the prevalence among those aged 65 and over with multiple conditions is much lower than for their younger counterparts, and is in fact often closer to the levels experienced by those with one condition in the 16-54 age group. Therefore, it appears that adults with multiple conditions aged under 65 have a quite distinctive profile in terms of the burden of their low wellbeing, whereas those aged 65 and over share some experiences in common with younger people with lower condition burdens.

Figure 6.11 Prevalence of SWEMWBS >1 SD below mean, by age group and condition number (0, 1, 2 or more), SHeS 2008-2011

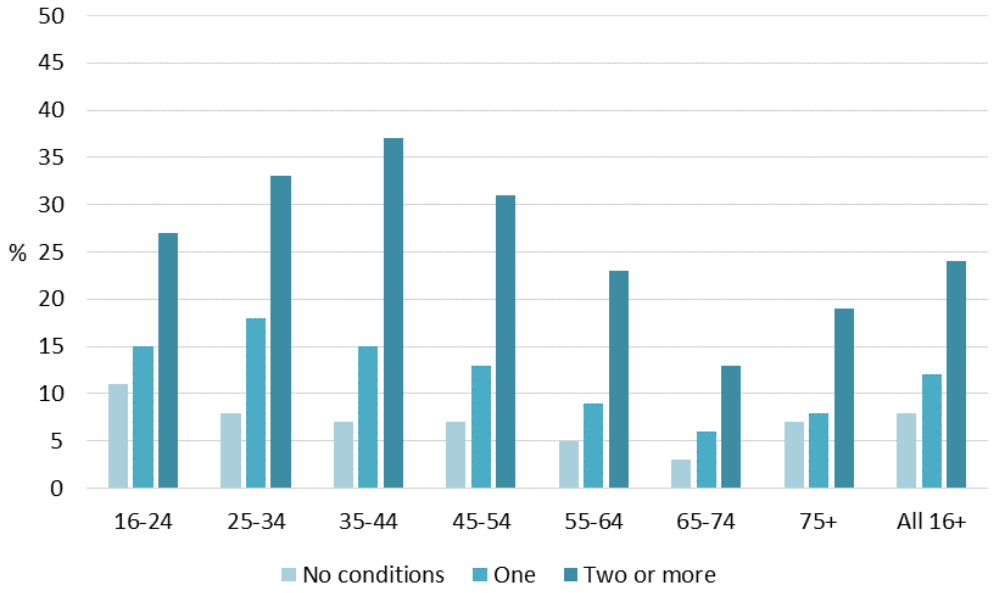
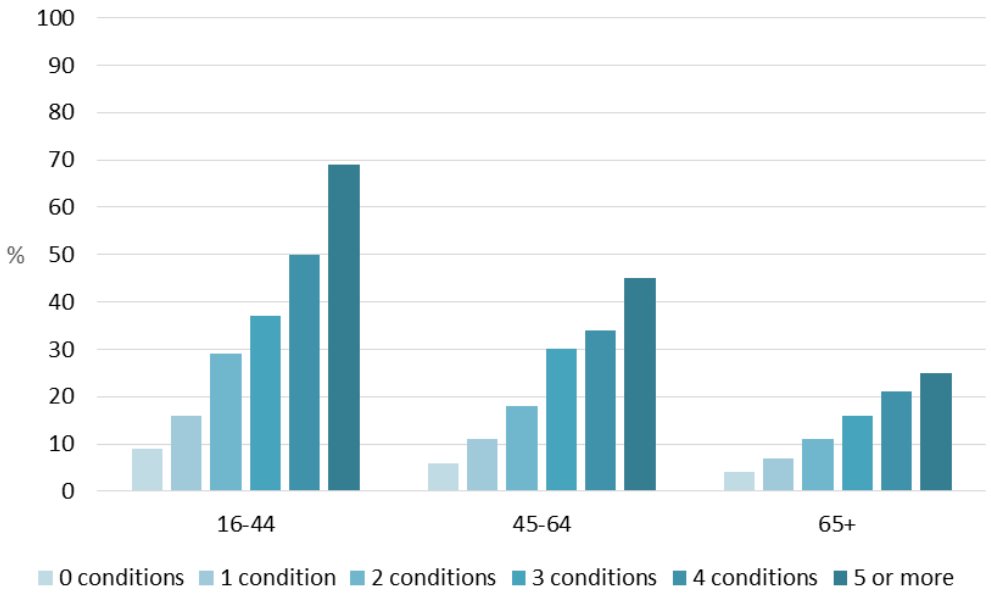


Figure 6.12 extends the number of conditions shown and confirms that even for those with the highest burden of conditions, age is a critical factor shaping levels of psycho-social functioning. Although it isn't possible to show the age groups with the finer detail used previously (due to sample size limitations), people aged 65 and over with five or more conditions had levels of psychosocial functioning that were similar to, or better than, those seen among people aged 16-44 with two or more conditions, and people aged 45-64 with three or more conditions.

Figure 6.12 Prevalence of SWEMWBS score >1 SD below mean by age group and condition number (0-5 or more), SHeS 2008-2011



Note: small sample sizes for 16-44 age group with 4 conditions (81) and 5+ conditions (69).

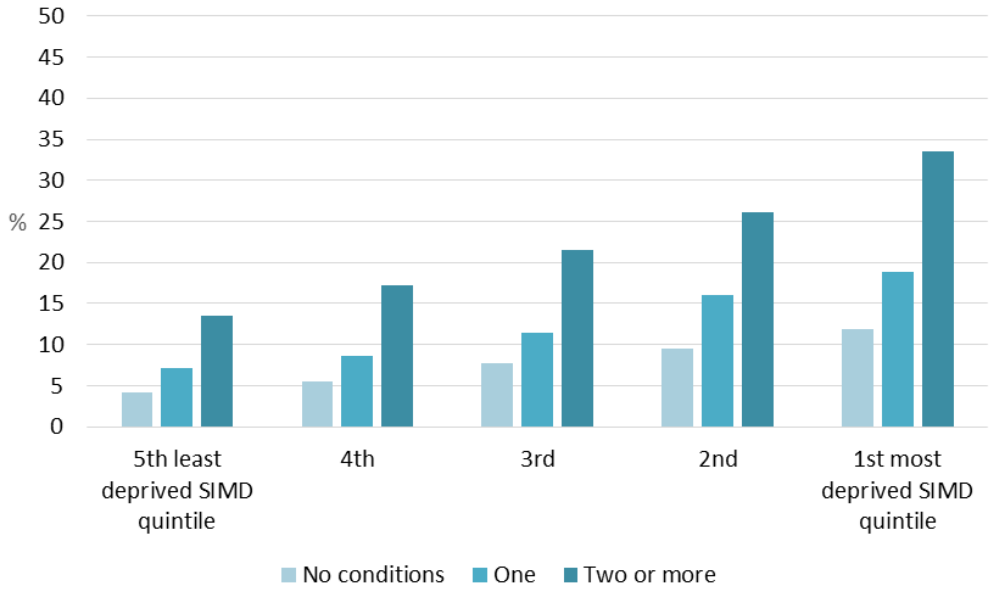
Additional analyses of variations by age group for the individual SWEMWBS items showed that they follow very similar patterns regardless of condition numbers, in terms of the items that showed the largest and smallest differences between the age groups. So while the overall scores differ (as already demonstrated above) with people with multiple conditions typically having lower scores for each item than those with one condition, the underlying nature of the two groups' wellbeing *patterns* are actually very similar (data not shown).

Condition number and area deprivation

Figure 6.4 at the start of the chapter showed the association between low wellbeing and condition number for each SIMD quintile; Figure 6.13 below replicates this. The progressive increase in low wellbeing by condition number is evident within each SIMD quintile. Furthermore, the size of the gap between people with multiple conditions and people with none increases markedly as deprivation increases, doubling between the least and most deprived quintiles. These patterns illustrate the way in which deprivation interacts with condition status to result in worsening

outcomes as deprivation increases. Another dynamic is also evident, as the impact of deprivation differs across the condition status groups, such that the absolute increase in low wellbeing related to deprivation is larger for those with multiple conditions than for the two other groups.

Figure 6.13 Prevalence of SWEMWBS >1 SD below mean, by condition number (0, 1, 2 or more) and SIMD quintile, SHeS 2008-2011

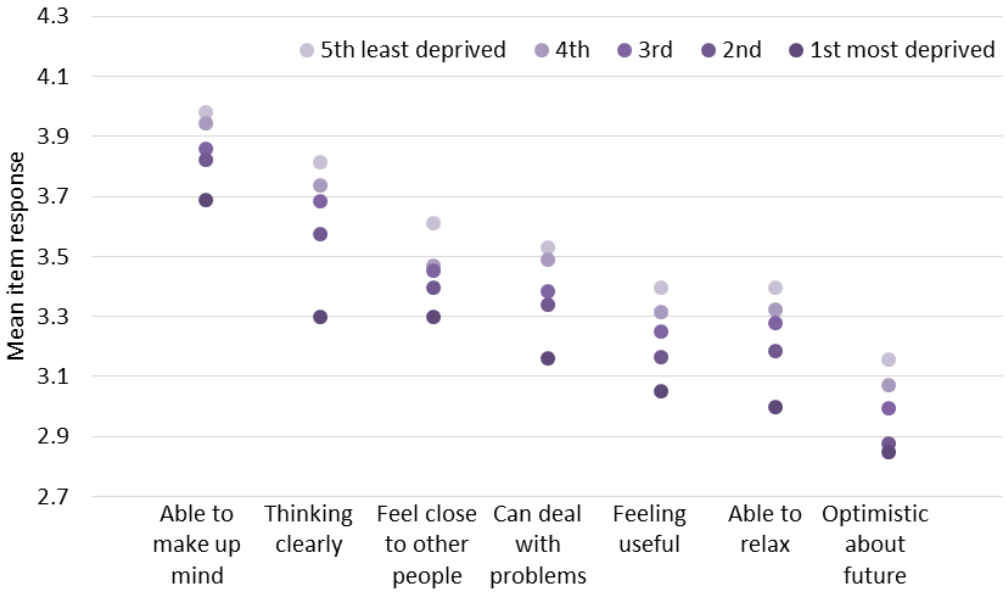


The combination of deprivation and ill-heath therefore appears to be particularly toxic for people's wellbeing: 33.5% of people with multiple conditions living in the most deprived areas have low wellbeing, compared with 13.5% of those with multiple conditions living in the least deprived areas. Conversely, and as seen with the results for different age groups, there are also some groups of people with multiple conditions who have better – or at least not notably worse – wellbeing than people with one or no conditions. The wellbeing of people living in the most deprived quintile who have no conditions, and those in the most and second most deprived quintiles who have one condition, is generally worse or matches that of people living in the least deprived areas who have multiple conditions.

Figures 6.14 and 6.15 show the individual SWEMWBS items' mean scores by SIMD quintile for people with multiple conditions, and one condition, respectively. Unlike

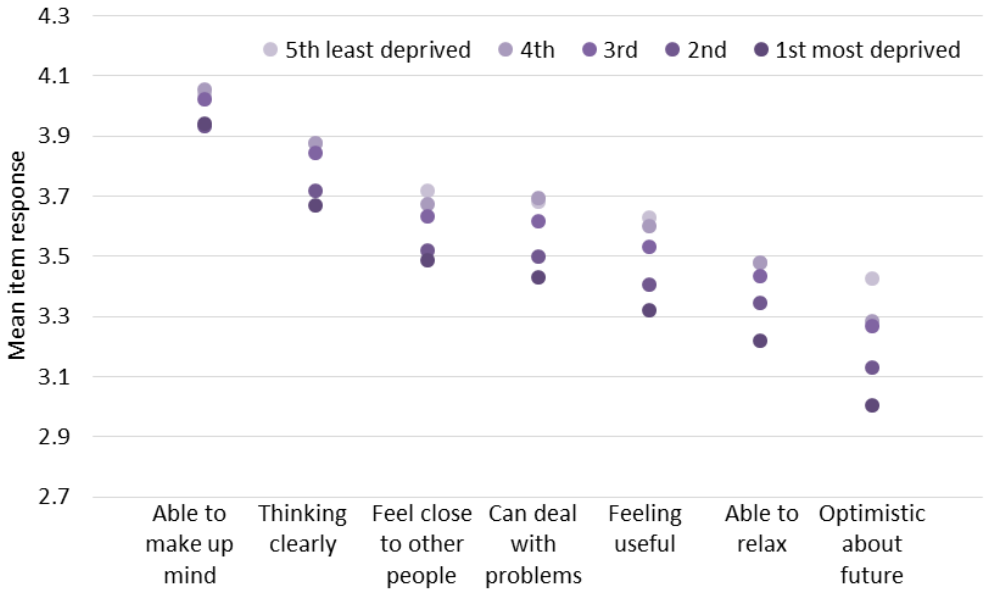
the equivalent analyses of age and SWEMWBS items discussed above, it is clear that both the absolute levels of low wellbeing and the nature of the variations in responses to items, differed by SIMD between those with multiple conditions and those with just one. This therefore illustrates that deprivation is not only associated with differences in absolute levels of wellbeing, regardless of condition number, but that it also shapes the way in which the individual measures underlying these summary patterns vary for people with multiple conditions compared to those with just one.

Figure 6.14 Individual SWEMWBS item mean scores by SIMD quintile – among people with multiple conditions, SHeS 2008-2011



Note: scale has been truncated for clarity, items were scored from 1-5.

Figure 6.15 Individual SWEMWBS item mean scores by SIMD quintile – among people with one condition, SHeS 2008-2011



Note: scale has been truncated for clarity, items were scored from 1-5.

Condition number, age and area deprivation

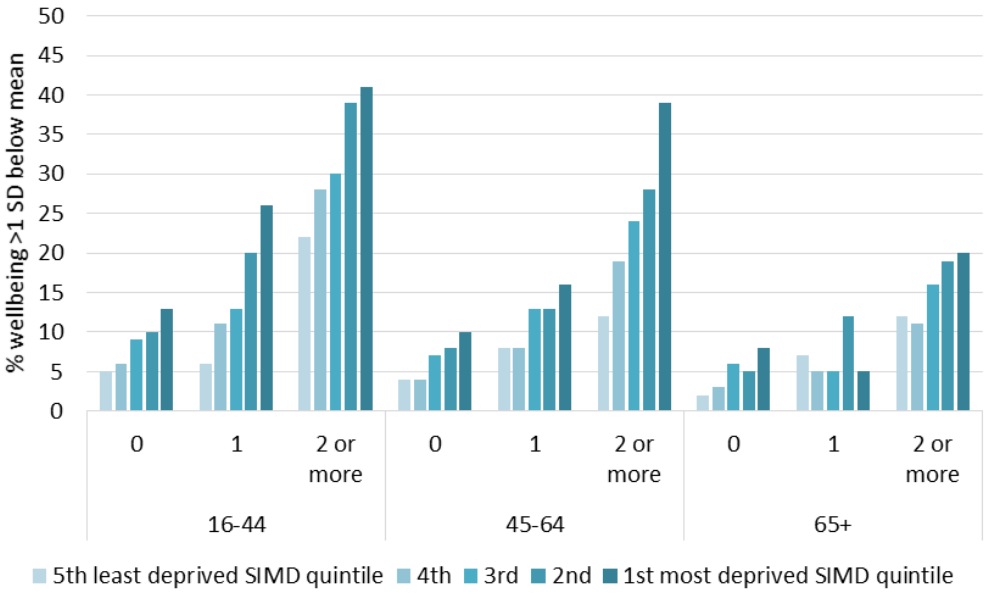
The previous two sections explored the stratification of outcomes by age, a non-modifiable risk factor, and deprivation, which is potentially modifiable, but rarely successfully. This section now explores the interplay of these two factors on the association between condition numbers and wellbeing. The aim is to better identify which specific groups in the population are most likely to experience impaired low wellbeing, and how this relates to their condition burden.

Figure 6.16 shows the association between low wellbeing and SIMD quintile separately for three age groups (16-44, 45-64, 65 and over). Within each age group, low wellbeing increases with deprivation, and with condition number, with the highest levels of low wellbeing experienced by people with multiple conditions living in the most deprived areas. The only notable exception is the pattern seen for people aged 65 and over with one condition (who represent a relatively small group overall). However, the gradients are less steep in the 65 and over age group, which echoes the flattening with age of the

SIMD gradient in the overall prevalence of multiple conditions illustrated in Chapter 5 (Figure 5.7).

Overall, the highest levels of low wellbeing among adults with multiple conditions are for those aged 16-44 and 45-64 living in the most deprived SIMD quintile, and those aged 16-44 living in the second most deprived SIMD quintile, with around four in ten of these groups experiencing this. Again, as the results presented so far have shown, the wellbeing of people aged 16-64 who do not have multiple conditions but who live in the most deprived areas is often worse than the wellbeing of people with multiple conditions living in the least deprived areas.

Figure 6.16 Prevalence of SWEMWBS score >1 SD below mean by condition number (0, 1 2 or more), age group and SIMD quintile, SHeS 2008-2011



The results of the final piece of analysis in this section are shown in Table 6.3, which presents the odds ratios (ORs) for having low wellbeing, unadjusted and adjusted for sex, age, deprivation and partnership status.[24] For each measure, the ORs are presented using the two condition number summary measures (0-5 or more; 0-2 or more). People with one condition were used as the reference category. In this way, it is possible to illustrate each additional condition's association with low wellbeing.

[24] Partnership status was included in the model because previous studies have consistently shown it to be associated with wellbeing, with marriage / cohabitation positively associated with higher wellbeing.

Compared with people with one condition, the unadjusted odds of having low wellbeing increased to being as much as 4.3 times higher for those with five or more conditions, and were 2.2 times higher for all those with multiple conditions. After adjustment, these ORs changed remarkably little, to 5.2 and 2.4, respectively, and the four adjustment factors all remained significantly associated with having low wellbeing, independent of condition status. This therefore confirms that the association between condition numbers and wellbeing is not confounded by these additional factors (if they had been, the ORs would be expected to decrease).

Table 6.3 Unadjusted and adjusted odds ratios for low wellbeing by condition number (0-5 or more; 0, 1, 2 or more), SHeS 2008-2011

SWEMWBS Score >1 SD below mean	**Unadjusted OR**	**95% CI[a]**	**Adjusted[b] OR (sex, age, area deprivation, & partnership status)**	**95% CI[a]**
Number of conditions (p<0.001)				
No conditions	0.6	0.5-0.6	0.5	0.4-0.6
One condition (reference category)	1.0			
Two	1.6	1.5-1.8	1.8	1.6-2.0
Three	2.4	2.1-2.7	2.8	2.4-3.2
Four	3.0	2.5-3.5	3.4	2.8-4.1
Five or more	4.3	3.6-5.1	5.2	4.3-6.2
Two or more	*2.2*	*2.0-2.5*	*2.4*	*2.2-2.7*

[a]p value for all ORs <0.001, unless stated otherwise.
[b]OR estimates for adjustment factors are shown in Table I3, Appendix I.

Condition number, severity, age and area deprivation

This section adds a further dimension to the analyses presented above by examining whether the patterns seen so far are related to having a condition that limits daily activities.

Conditions that limit daily activities are typically considered to be more severe, both in terms of their potential to shorten people's lives, and their potential to reduce the quality of those lives, via the symptom burdens imposed, which are often the cause of the limitations that people report. A measure of activity limitations therefore captures aspects of both the physiological severity of a condition as well as its wider psycho-

social consequences. The analyses presented below explore the extent to which the psycho-social functioning patterns outlined above are related to people's experiences of limitations on their activities. A note of caution on how this was measured is necessary before proceeding. As Chapter 3 outlined, everyone who mentioned a long-term condition at the unprompted question was further probed to see if they felt that it limited their daily activities. No such information was collected in follow-up to the questions about additional CVD conditions or other health problems (which, in some circumstances, contributed to the multiple condition measure, as set out in Chapter 5). This measure of limitations is therefore likely to be an underestimate, on the assumption that at least some of the people who mentioned other conditions or health problems will also have experienced some resulting limitations. This is reflected in the fact that 62.0% of people newly defined as having multiple conditions (via the stages outlined in Chapter 5) had a limiting condition, compared with 73.9% of those whose status did not change and 89.9% of those whose condition number was extended. For this reason a count of the number of limiting conditions has not been integrated into this analysis; it instead uses a binary measure of whether any limiting conditions were reported or not.

Before looking at the role that activity limitations play in shaping people's experiences, it is useful to look at the population prevalence of conditions with and without such limitations. In total, 26.7% of adults reported at least one activity limiting condition and 21.3% had at least one condition without limitations. Table 6.4 shows these figures split by condition number, as well as their distributions by age group and SIMD quintile. The most striking age-related pattern is found among people with multiple conditions, at least one of which is limiting, where prevalence increases from 7.4% in the 16-44 age group to 21.7% for those aged 45-64 and to 40.5% for those aged 65 and over. The steepest SIMD gradient is also evident for people with multiple conditions and activity limitations, with prevalence just over doubling from 12.0% to 26.4% between the least and most deprived quintiles. In contrast, differences by age were much less notable, and differences by SIMD were negligible or non-existent, for the groups with one condition (regardless of limitations), or with multiple conditions but no limitations. The absence of gradients for these outcomes is not typical of the

results usually seen in most chronic disease epidemiology and their implications are considered further in the discussion in Chapter 7. Focusing just on those with conditions, over half (55.6%) reported activity limitations, and this was very much linked to the overall number of conditions reported: 75.6% of adults with multiple conditions reported activity limitations, compared with 32.8% of those with one condition.

Table 6.4 Prevalence of limiting and non-limiting conditions by age group and SIMD quintile, SHeS 2008-2011

		No conditions	1 non-limiting	1 limiting	2 or more, none limiting	2 or more, at least 1 limiting	*Sample size*
All adults	**%**	51.9	15.2	7.9	6.1	18.8	*28,772*
Age group							
16-44	**%**	71.4	11.3	7.6	2.2	7.4	*11,080*
45-64	**%**	43.9	18.2	8.6	7.6	21.7	*10,297*
65+	**%**	19.9	19.4	7.5	12.6	40.5	*7395*
SIMD quintile							
5th least deprived	**%**	58.3	16.4	6.7	6.6	12.0	*5079*
4th	**%**	54.5	17.0	7.6	5.6	15.4	*6489*
3rd	**%**	51.3	15.3	7.9	6.5	18.9	*6102*
2nd	**%**	49.9	14.3	7.9	6.2	21.6	*5484*
1st most deprived	**%**	45.5	13.0	9.5	5.6	26.4	*5618*

Table 6.5 below shows that levels of low wellbeing were broadly similar (7.5-9.6%) for people with multiple conditions, but no reported limitations, and those with one non-limiting condition or no conditions at all. In contrast, both groups of people with a limiting condition had higher levels of low wellbeing, with the burden felt most by those with multiple conditions - at least one of which imposes activity limitations.

Table 6.5 Prevalence of low wellbeing by number of limiting conditions, SHeS 2008-2011

	No conditions	1 non-limiting	1 limiting	2 or more, none limiting	2 or more, at least 1 limiting
	%	**%**	**%**	**%**	**%**
Low wellbeing	7.5	8.6	19.0	9.6	28.2
Sample size	*12,571*	*4224*	*2156*	*1802*	*5480*

Figure 6.17 illustrates how the age gradients in wellbeing seen above are more apparent among people with activity limitations, particular in the presence of multiple conditions. Similarly, Figure 6.18 shows how the SIMD gradients in wellbeing are far steeper for those with activity limitations. In both cases, the experiences of people with non-limiting conditions are very similar regardless of condition number. And, echoing the patterns seen previously (e.g. in Figure 6.16), the results in Figure 6.18 show how the wellbeing of people with one limiting condition living in the three most deprived quintiles was equal to, or worse than, the levels experienced by people with multiple conditions (including limitations) living the three least deprived quintiles.

Figure 6.17 Prevalence of SWEMWBS >1 SD below mean by condition number (1, 2 or more), presence of a limiting condition and age group, SHeS 2008-2011

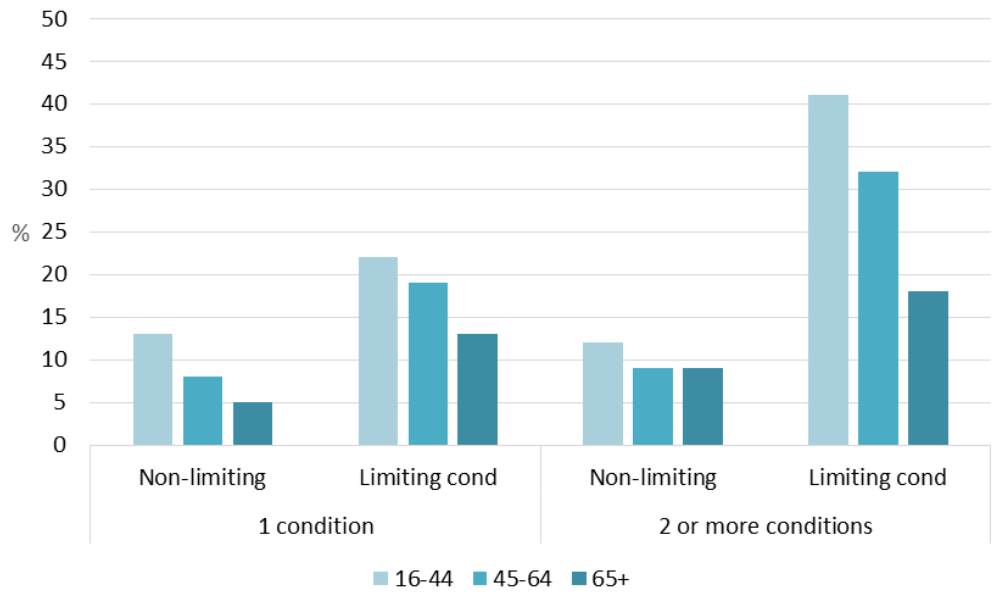
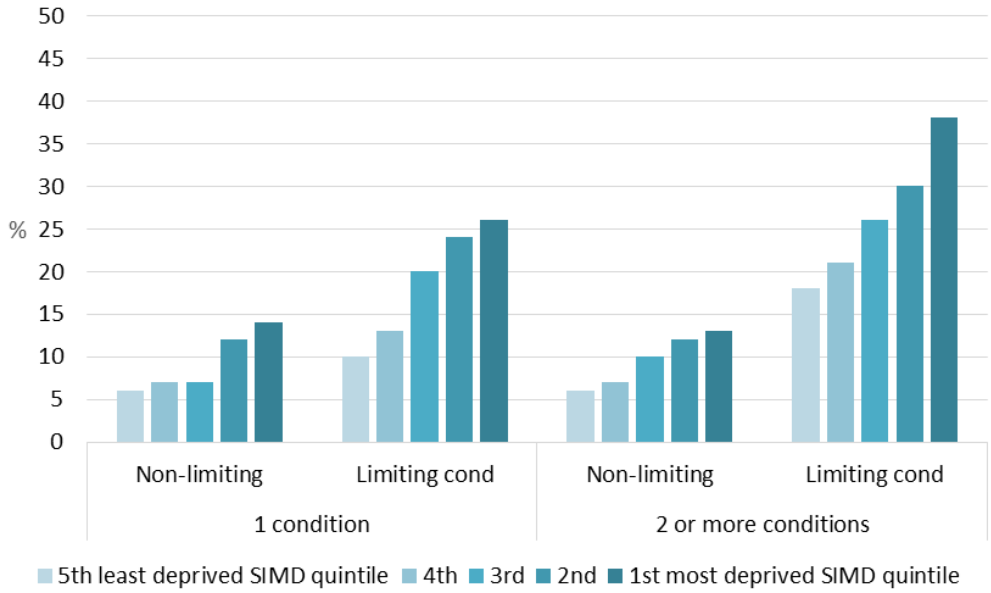


Figure 6.18 Prevalence of SWEMWBS >1 SD below mean by condition number (1, 2 or more), presence of a limiting condition and SIMD quintile, SHeS 2008-2011



The odds ratios in Table 6.6 confirm the importance of activity limitations in explaining the association between condition status and low wellbeing. Looking first at the unadjusted results, compared with people with one non-limiting condition, people with one limiting condition have higher odds of low wellbeing (OR 2.5) than people with multiple conditions but no reported activity limitations (non-significant OR of 1.1). Those with multiple conditions and activity limitations had the highest odds of low wellbeing (OR 4.2). After adjusting for age, sex, area deprivation and partnership status these figures changed a little, to 2.1, 1.3 and 4.3, respectively, and the OR for people with multiple conditions but no limitations (1.3) tips into being statistically significantly higher, but only marginally so. The sustained significance of factors such as age and area deprivation (with low wellbeing less common in older age groups, and more common as deprivation increases) confirm the patterns evident in the above graphs which showed how these factors were associated with outcomes when the analyses were stratified by limiting condition status (results shown in Table I4, Appendix I).

Table 6.6 Unadjusted and adjusted odds ratios for low wellbeing by limiting condition status, SHeS 2008-2011

SWEMWBS Score >1 SD below mean	Unadjusted OR	95% CI[a]	Adjusted OR[b] (sex, age, area deprivation & partnership status)	95% CI[a]
Condition status				
One non-limiting condition (reference category)	1.0		1.0	
No conditions	0.9	0.8-1.0	0.7	0.6-0.8
One limiting condition	2.5	2.1-2.9	2.1	1.8-2.5
Two or more conditions, no reported limitations	1.1	0.9-1.4 [n.s.]	1.3	1.04-1.6 [p=0.02]
Two or more conditions, at least one limiting	4.2	3.7-4.7	4.3	3.7-4.9

[a]p value for all ORs <0.001, unless stated otherwise.
[b]OR estimates for adjustment factors are shown in Table I4, Appendix I.

Potential mechanisms behind variations in wellbeing

Introduction

The results presented in the chapter so far help to signpost the groups in the population most likely to be at risk of low wellbeing. However, they offer little by way of explanation, both in terms of the mechanisms explaining the overall association between conditions and functioning, or the age and deprivation-related patterns behind this. This section explores a number of possible explanations. The first is a function of the survey process itself and concerns the fact that using a paper self-completion to measure wellbeing might have biased the results. Around one in ten participants did not complete these questions. If those who did not complete them had lower levels of wellbeing that those who did this would results in bias if they were found to be concentrated in particular sub-groups. Beyond the survey process, another possible mechanism that can be explored is whether there is a differential burden by age or deprivation group in the experience of limiting conditions – which was shown to be strongly associated with wellbeing. Different experiences of illness is also explored, briefly, by looking at some of the wider socio-economic characteristics of people with multiple conditions across the age spectrum. Finally, the issue of survivorship bias is examined to see whether the oldest age group with multiple conditions included in the survey in 2008-11 were comprised of healthy survivors, with

better health than would be expected as a result of premature mortality among their less healthy peers.

Non-response bias

The discussion here concerns the way wellbeing was measured within the survey. The broader issue of non-response bias as a consequence of non-participation in the survey at any stage is considered in the discussion chapter. As Chapter 3 outlined, to preserve participants' confidentiality around the potentially sensitive topics covered by WEMWBS (and GHQ12) the questions were asked as part of a paper self-completion, offered during the main interview stage. Around one in ten adults (9.5%) did not complete the WEMWBS questions. In the majority of cases (around three-quarters) this was due to refusing the whole self-completion, rather than missing those items in particular. Table 6.7 below shows how levels of missing WEMWBS data differed by age, SIMD, condition status (using the definition which incorporates severity) and life satisfaction (measured on a scale from 0 to 10). Table 6.8 extends this by showing how the variations by condition status and life satisfaction differed by age group. The life satisfaction measure is useful here because it is the only measure of wellbeing included in the main interview so has virtually no missing data. So while it lacks the insights about experiences that underpin WEMWBS, it can serve as an additional indicator of wellbeing to help establish the consequences, if any, of the missing data for the other measures. It is a fairly basic measure, with a very skewed distribution (the modal answer is 8); results are presented here for scores of 0-5 and 6-10 (covering 13.7% of the population, scores of 0-5 were the closest fit with the low wellbeing measure).

Table 6.7 Prevalence of missing WEMWBS data by age group, SIMD quintile, condition status and life satisfaction, SHeS 2008-2011

		WEMWBS missing	*Sample size*
Age group			
16-24	**%**	8.3	*2556*
25-34	**%**	7.3	*3702*
35-44	**%**	7.4	*4829*
45-54	**%**	7.3	*5236*
55-64	**%**	8.0	*5064*
65-74	**%**	10.8	*4207*
75+	**%**	20.1	*3191*
SIMD quintile			
5th least deprived	**%**	8.1	*5082*
4th	**%**	8.7	*6490*
3rd	**%**	8.8	*6106*
2nd	**%**	9.8	*5486*
1st most deprived	**%**	12.1	*5621*
Condition status			
0 conditions	**%**	8.1	*13,611*
1 non-limiting condition	**%**	8.8	*4593*
1 limiting condition	**%**	10.1	*2376*
2 conditions, non-limiting	**%**	9.0	*1967*
2 conditions, at least 1 limiting	**%**	12.8	*6225*
Life satisfaction score			
0-5	**%**	13.1	*3917*
6-10	**%**	8.7	*24,774*

Note: all figures are unweighted.

The key points are that missing data increases with age and area deprivation and is highest among those with limiting conditions and low life satisfaction. Stratifying by age reveals that these patterns were all more pronounced for the oldest age group; for example, just over a fifth of those aged 65 and over with low life satisfaction had no WEMWBS data. The data cannot, on the basis of these patterns, be considered to be missing completely at random (formal tests of this confirmed this, see the additional information in Appendix I).

Table 6.8 Non-response to WEMWBS by condition status and life satisfaction by age group, SHeS 2008-2011

	Age group		
	16-44	**45-54**	**65+**
Condition status	**%**	**%**	**%**
0 conditions	7.7	7.1	13.0
1 non-limiting condition	6.4	6.9	13.3
1 limiting condition	7.9	6.6	19.8
2 conditions, non-limiting	4.9	8.5	10.6
2 conditions, at least 1 limiting	8.4	9.5	16.8
Life satisfaction score			
0-5	9.1	10.7	22.8
6-10	7.2	7.0	13.3
Sample sizes			
0 conditions	*7714*	*4402*	*1495*
1 non-limiting condition	*1258*	*1885*	*1450*
1 limiting condition	*902*	*924*	*550*
2 conditions, non-limiting	*265*	*769*	*933*
2 conditions, at least 1 limiting	*941*	*2317*	*2967*
Life satisfaction 0-5	*1277*	*1674*	*966*
Life satisfaction 6-10	*9780*	*8601*	*6393*

Note: all figures are unweighted.

These patterns of missing data mean that the possibility that the lower levels of impaired wellbeing found among older people with multiple conditions could, in part, be a consequence of non-response bias (because older people with low wellbeing are disproportionately missing from the data). Two pieces of evidence can be offered to discount this as major source of bias. The first is the fact that the distribution of low levels of life satisfaction (scores of 0-5) by age group and condition number broadly follows the same patterns seen for SWEMWBS (see Figure 6.19). Sensitivity analysis using different life satisfaction score thresholds generated the same patterns (data not shown). The second is that using multiple imputation (Sterne et al. 2009) to assign values to the missing SWEMWBS cases does not yield a notably different set of results compared with the original, based on a complete case analysis (see Figures 6.20 and 6.21 below; full data is contained in Table I1, Appendix I). To further assess this, the regression reported in Table 6.6 above was replicated using life satisfaction scores of 0-5 as the outcome of interest, and this resulted in almost identical results to the original

SWEMWBS analysis (full details of the imputation methods used, and the results of these additional analyses, are in Appendix I).

Figure 6.19 Prevalence of low levels of life satisfaction (scores of 0-5) by condition number (0, 1, 2 or more) and age group, SHeS 2008-2011

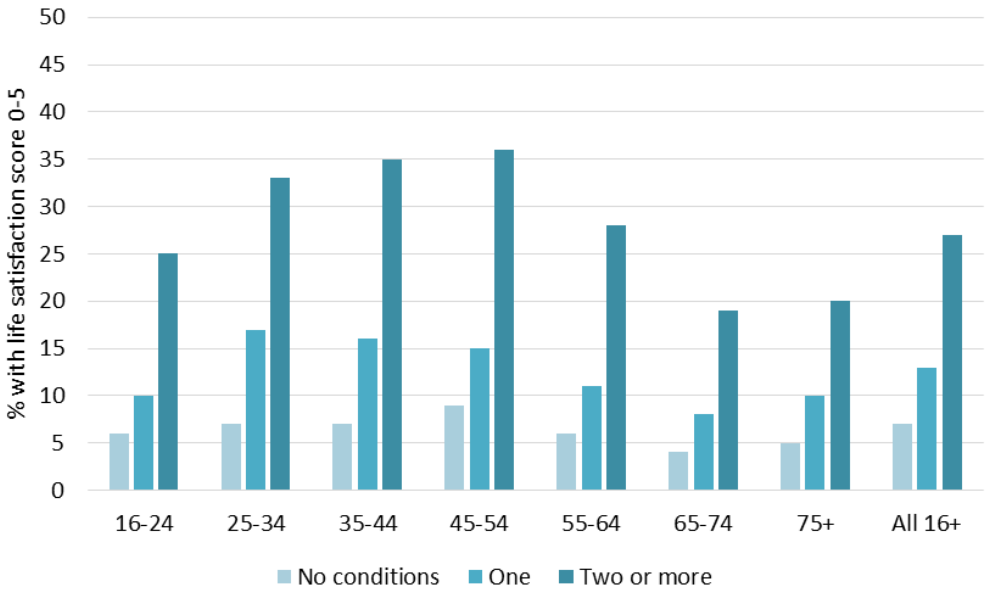


Figure 6.20 Prevalence of SWEMWBS >1 SD below mean, by age group and condition number (0, 1, 2 or more), SHeS 2008-2011 - original data

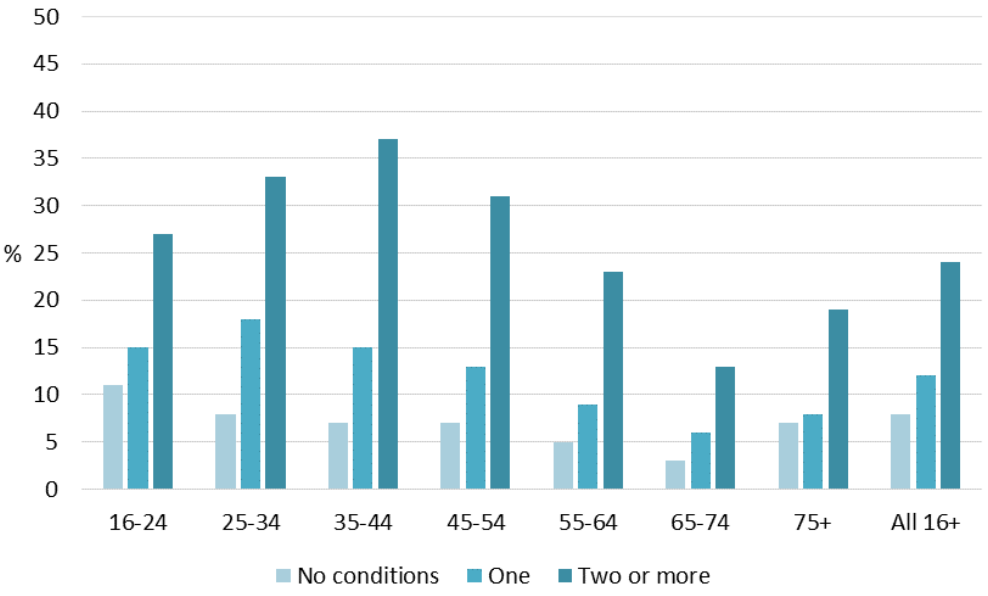
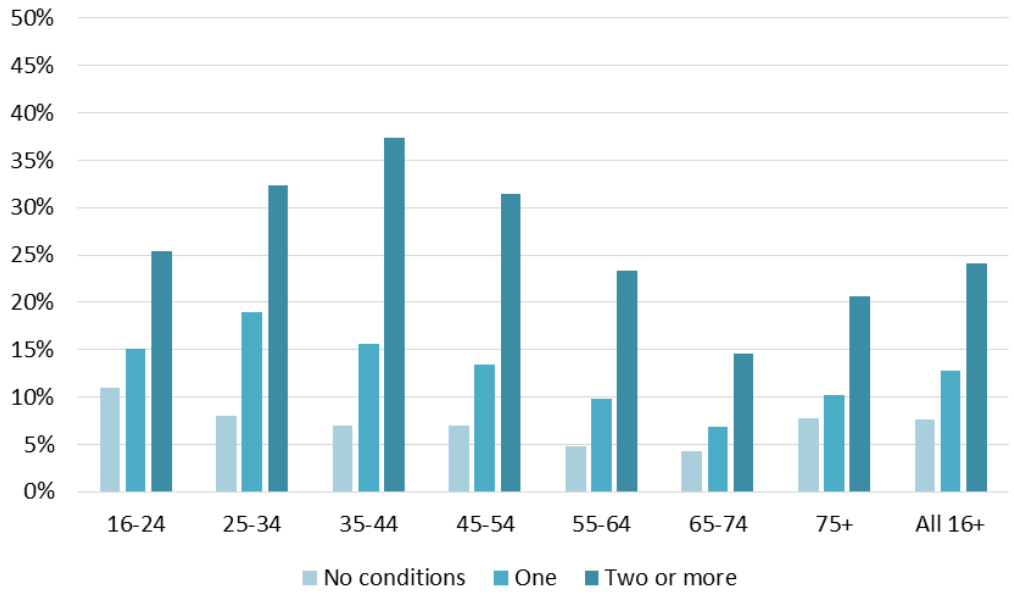


Figure 6.21 Prevalence of SWEMWBS >1 SD below mean, by age group and condition number (0, 1, 2 or more), SHeS 2008-2011 - following multiple imputation of missing data



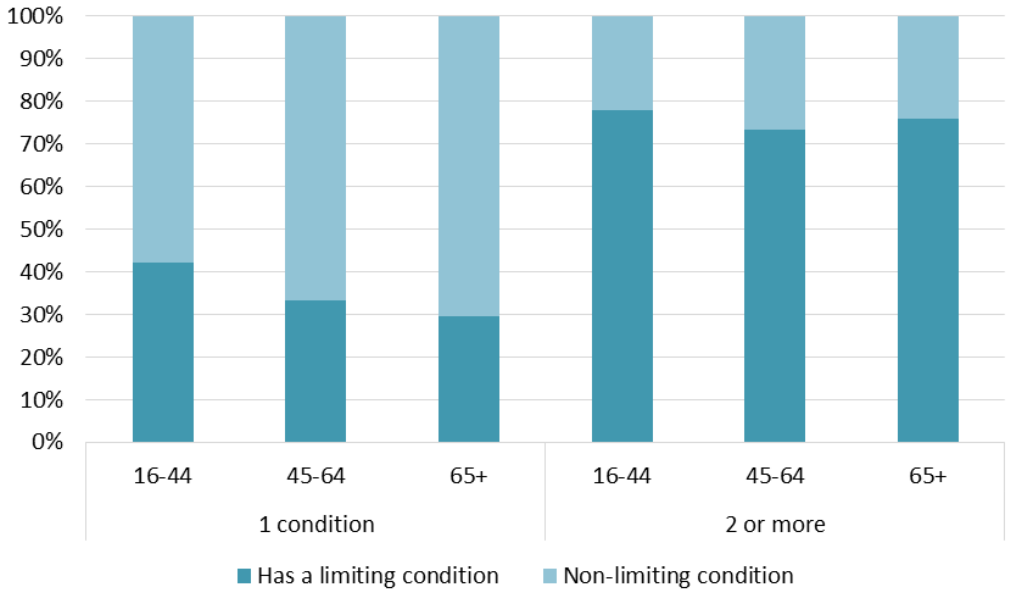
Missing data is a perennial problem in population survey research so their potential to bias results must always be considered. However, as the results here demonstrate, the characteristics of the people who do not provide complete information need to be consistently and notably different in order for their absence to exert a significant degree of bias. While older people with low levels of life satisfaction were overly represented among those with missing data when compared with other age groups, the overall composition of this group was sufficiently diverse to ensure that the age-related patterns in wellbeing by condition status were not an artefact of missing self-completion data. The extent to which other forms of missing data, due to overall survey non-response, might have biased these results, and the extent to which household surveys underrepresent the experiences of older populations, are discussed further in Chapter 7.

Differential burdens in condition severity

As already noted, the majority of people with multiple conditions have activity limitations, whereas only a minority of those with one condition do. This is therefore likely to help account for the overall difference in wellbeing evident between those with and without multiple conditions. In contrast, as Figure 6.22 illustrates, the lack of

an association between age and the presence of limitations, among those with multiple conditions, means that their age-related patterns in wellbeing cannot be attributed to a differential burden of activity limiting conditions by age group (though this might be case for younger people with single conditions). However, although the *prevalence* of activity limitations among those with multiple conditions does not vary by age group, it is still possible that the *experience and consequences* of living with such limitations differs markedly between younger and older people. And it is these experiences that explain why having multiple conditions, a high proportion of which are deemed limiting, is accompanied by notably low levels of wellbeing in people under 65. This is explored, a little, in the next section; though clearly these kinds of insights stretch the possibilities of quantitative data.

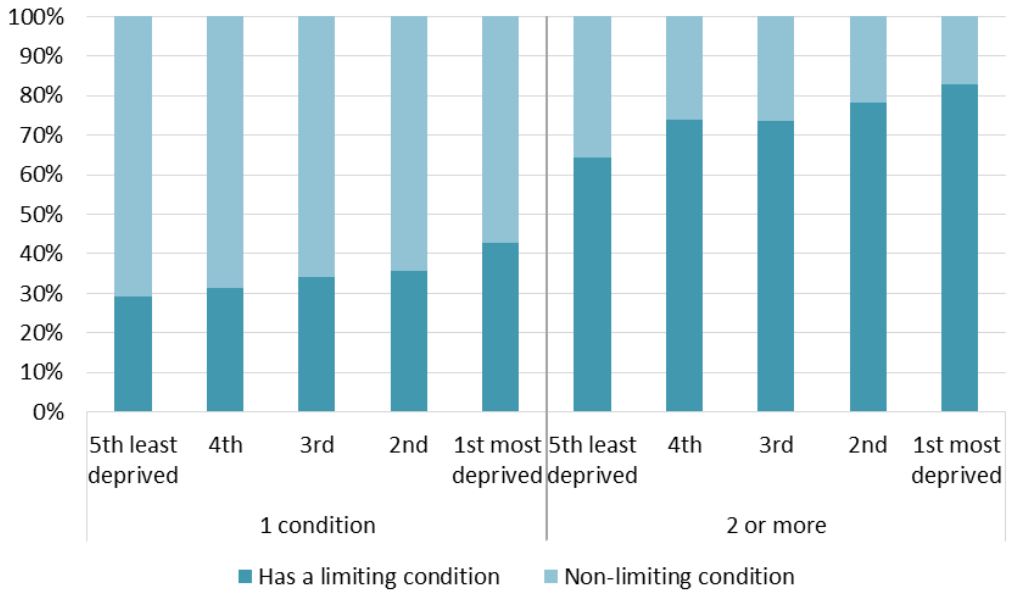
Figure 6.22 Prevalence of limiting and non-limiting conditions among people with conditions, by age group and condition number (1, 2 or more), SHeS 2008-2011



The results in Figure 6.23 apply a similar approach, but this time with area deprivation. The proportion of those with conditions who report activity limitations increases in line with deprivation. However, the level of limitations found among people with one condition living in the most deprived areas is still lower than the level seen in people with multiple conditions in the least deprived areas. The social

patterning of the prevalence of activity limitations would also appear to be an unlikely source of the differences seen in wellbeing. Again, however, the possibility that differences exist in how these are experienced cannot be discounted.

Figure 6.23 Prevalence of limiting and non-limiting conditions among people with conditions, by SIMD quintile and condition number (1, 2 or more), SHeS 2008-2011



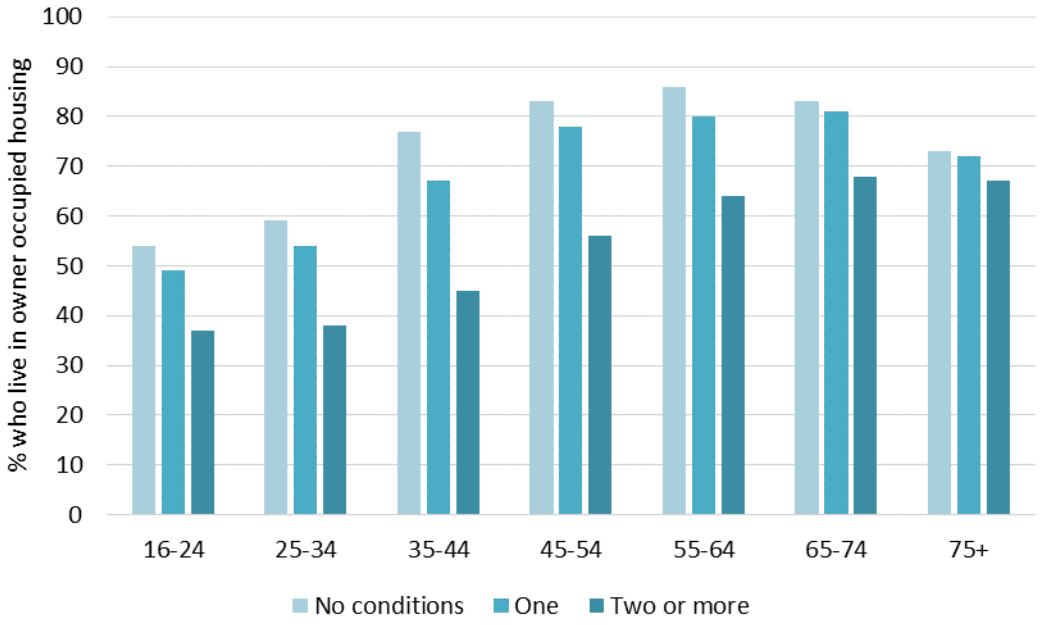
Differential illness experiences

Many, if not most, of the explanatory mechanisms behind these patterns will lie beyond the reach of the data to hand. For example, one possible explanation for the increased levels of impaired psycho-social functioning among younger adults with multiple conditions is that the consequences of living with activity limitations are worse for younger people than older age groups, resulting in greater impairments to psycho-social functioning. It is clearly far rarer for younger people to have multiple limiting conditions than it is for older people, hence the sense of difference and exclusion felt by younger people relative to their peers will be more acute. This kind of explanation therefore moves beyond simply the quantitative identification of whether someone has a limiting condition, and instead attempts to unpick why that status might have different impacts for different types of people. These questions are more typically explored using qualitative methods, and have been, as the literature review in Chapter 2 outlined (see, for example, O'Brien et al. 2014; Duguay et al. 2014).

However, some of these possible mechanisms or contextual experiences can be explored quantitatively. For example, the societal implications of poor health during working age will mean, for many, absence from the labour market and exposure to the welfare benefit system, which has become increasingly punitive towards those claiming disability or sickness-related benefits in recent years. This status could therefore result in psychological distress by virtue of the associated stigma of occupying a marginalised position in the labour market, but also through the stress involved with interacting with a stressful welfare system. In contrast, older people's income sources are largely seen as earnt entitlements, are less stigmatised, and typically involve fewer direct interactions with the apparatus of the welfare state. Half (47.9%) of adults aged 16-64 with multiple conditions were economically[25] active compared with 72.6% of those with one condition and 79.3% of those with none. Following from this, 27.7% of adults with multiple conditions of working age were classified as permanently unable to work due to sickness compared with 5.2% and 0.2% of those with one and no conditions, respectively. Another measure of economic capital, and also of relative residential stability – home ownership (with or without a mortgage) – was also clearly associated with condition status, as shown in Figure 6.24. At every age, people with multiple conditions were the least likely to live in a household that owned their property,[26] but more importantly, the gap between this group and those with no conditions reduced as age increased. The limitations placed on access to credit following the financial crisis of 2008, coupled with a more precarious labour market, will likely have exacerbated these patterns. And while home ownership is now becoming less common than in the past, the continued political salience of affordable housing, and of initiatives to support first time buyers, underline its status as an important social aspiration in the UK.

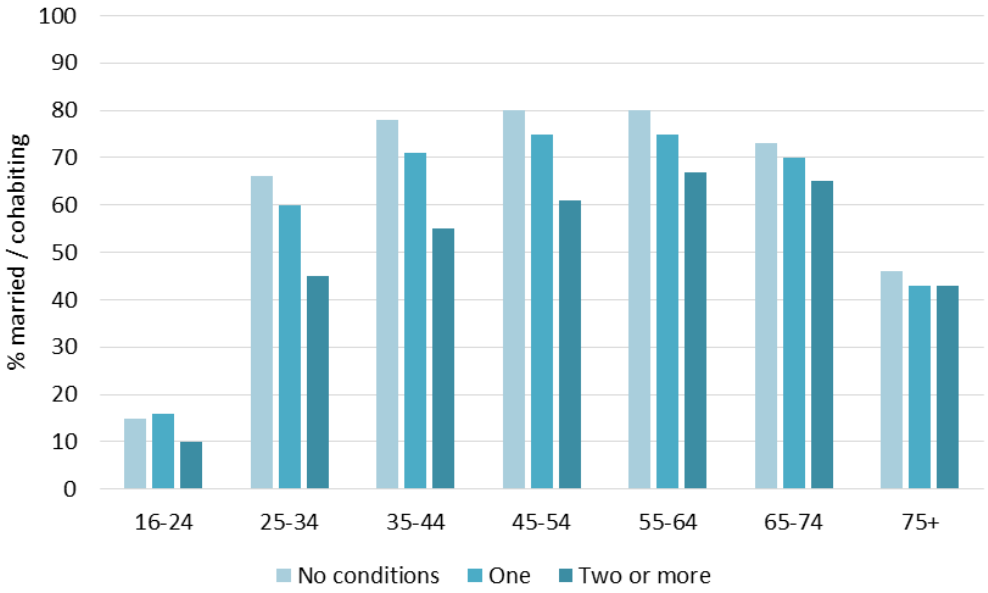
[25] In paid work, self-employed, on a government training scheme, waiting to take up paid work, or actively seeking paid work.
[26] Note that this is a measure of the tenure status of the household, hence the relatively high levels of ownership reported by younger people, many of whom were living in their parents' homes.

Figure 6.24 Prevalence of living in owner-occupied housing by condition number (0, 1, 2 or more) and age group, SHeS 2008-2011



These economic measures can be supplemented with examples from other aspects of people's social life experiences, such as forming relationships. Partnership status was included in the regression models presented above which identified its independent association with low wellbeing, and showed it was more common in single (never married), divorced, separated and widowed people than in married / cohabiting people. The positive benefits of having a co-resident partner will include an increased likelihood of access to social, practical and emotional support, which could all contribute to better psycho-social outcomes for someone living with poor health. In addition, the emotional trauma that accompanies divorce, separation and widowhood could confer additional assaults on people's wellbeing, over and above the experience of living without a co-resident partner. Moreover, forming a long-term partnership is a social norm that, based on the evidence in Figure 6.25, appears to be less commonly experienced by people with multiple conditions than those with none, especially in the under 65 age group (with the gap around 20 p.p. for those between the ages of 25-34 and 45-54).

Figure 6.25 Proportion of adults who were married or cohabiting, by condition number (0, 1, 2 or more) and age group, SHeS 2008-2011



Similarly, people with multiple conditions aged between 35-44 and 55-64 were twice as likely to be living alone following divorce or separation than their counterparts with no conditions (although absolute rates were quite low, 8-15% of people with multiple conditions in these age groups fell into this category). In contrast, rates of widowhood were broadly similar between the condition groups at all ages.

These measures of partnership status were taken at one point in time and only recorded information about people's living arrangements at the time of the survey. Many of the people without a co-resident partner will nevertheless have had a non-resident partner (conferring some of the advantages listed above), while some of those married or cohabiting will have previously experienced a divorce or separation or death of a partner. But, imperfect as they are, they do provide – in conjunction with above results about housing tenure and employment status - further evidence that the lives of working-age people with multiple conditions are both more economically challenging, and more divergent from, the social norms enjoyed by their same aged peers, than is the case for those in retirement. The potential for the identification of such mechanisms to help understand the wellbeing patterns presented here is discussed in Chapter 8.

Survivorship bias

Another possibility is that the older group represents a cohort of "healthy" survivors, their less healthy counterparts having already succumbed to premature mortality. Linked to this is the duration of people's symptoms. Developing multiple conditions at an older age, having previously been relatively healthy, is likely to result in a very different set of life experiences and psycho-social consequences, than developing multiple conditions at a younger age, and living with them across the lifecourse. Similarly, the combined experience of deprivation and poor health, which confers a particular toll in terms of people's wellbeing, has long been known to account for socio-economic differentials in life expectancy. Finally, it is also possible that higher levels of psycho-social impairment at younger ages itself contributes to a higher risk of premature mortality, which would be another potential mechanism for a healthy survivor effect being evident at older ages.

Cross-sectional data cannot unpick these kinds of dynamics; however, survival analysis using the 1998 data can shed some light on them, to a limited extent. These three factors are obviously related in the ways already described in this chapter. Similarly, reverse causation needs to be considered - someone's deprivation status could be a function of their health (via downward social mobility), and whether psychological distress is a cause, consequence or unhappy coincidence of poor physical health is a subject of debate. However, the point of the analysis presented below is not to try and explain differential mortality outcomes by condition number. It is designed to see whether higher levels of mortality among working age people with multiple conditions might help explain why low wellbeing is subsequently less common among the older population with multiple conditions.

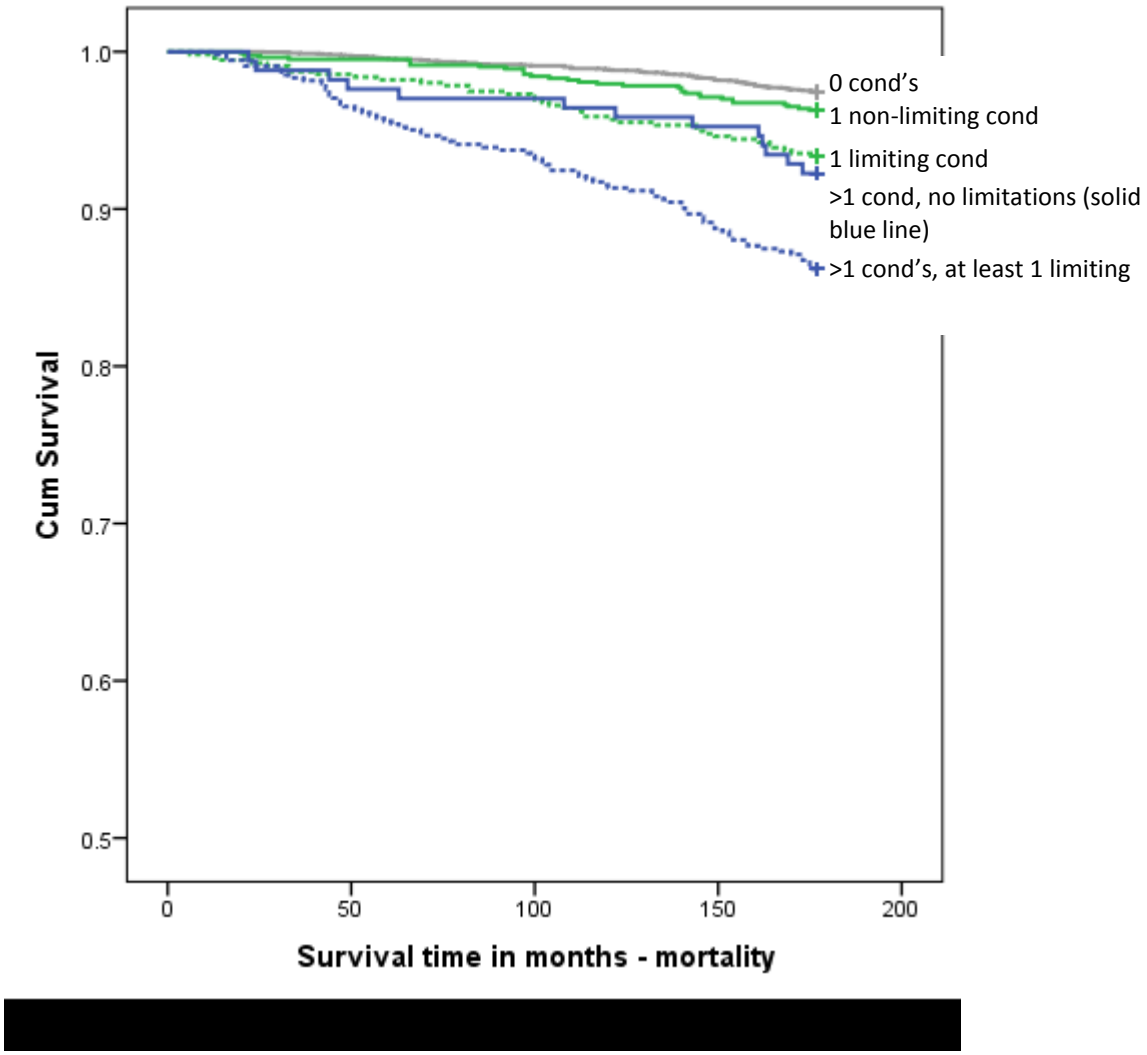
Severity

The survival curves in Figure 6.26 show the association between condition number and activity limitations before the age of 55, and subsequent survival. Deaths in this age group were relatively rare in the follow-up period (248/5659), so note that the cumulative risk of death scale (y-axis) has been truncated to run from 0.5-1 to aid the interpretation of the graph. The upper age cut-off of 55 was chosen because, having

been interviewed in 1998/9, any deaths among these people in the follow-up period would have occurred before a maximum age of 68, and they are therefore the closest equivalent to the 65 and over age group within the 2008-11 survey – the group for whom the possibility of survivorship bias is being investigated. A cut-off point of 50 would have been more accurate, but age is included in the 1998 linked dataset in aggregate ten year groups, rather than in single years (to help preserve participant anonymity), so 54 was the closest that could be reached. However, as the point of this analysis is to look for potential mechanisms to spur further thinking, rather than to come to definitive conclusions, this approximation seems adequate for the task required.

The group with activity limitations and multiple conditions had the lowest survival rates, while those with one limiting condition had worse survival than those with one non-limiting condition, and, for most of the period, a very similar risk of death as those with two conditions with no reported limitations. This would lend some evidence to the suggestion that people with multiple conditions and activity limitations before retirement age - who have already been shown to have the lowest wellbeing – are disproportionately absent from older age groups as a result of premature death.

Figure 6.26 Kaplan-Meier plot of survival among adults aged 16-54, for the five long-term and limiting condition status groups (14.9 years' follow-up), SHeS 1998-SMR linked data



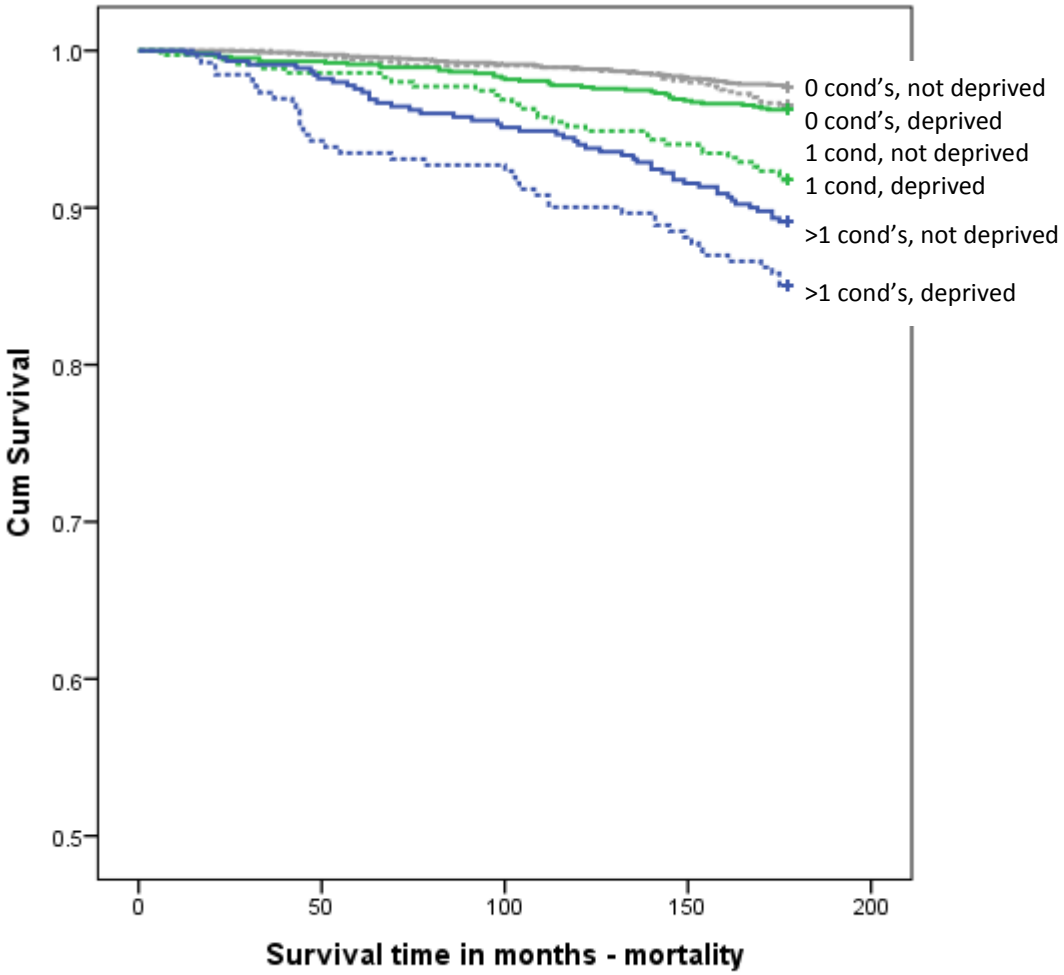
Note: scale has been truncated to aid interpretation (full scale runs from 0-1).

Deprivation

The next set of survival curves show the risks of death separately for the three condition groups, split between those living in the bottom 25% most deprived areas, as measured by the Carstairs index (the deprivation measure in common use at the time of 1998 survey). Having one or multiple conditions and living in a deprived area was clearly associated with an increased risk of dying, relative to their non-deprived counterparts with the same condition number. Though people with multiple

conditions who did not live in a deprived area had worse survival than those with single conditions living in deprived areas.

Figure 6.27 Kaplan-Meier plot of survival among adults aged 16-54, for the six long-term condition and Carstairs deprivation status groups (14.9 years' follow-up), SHeS 1998-SMR linked data



Note: scale has been truncated to aid interpretation (full scale runs from 0-1).

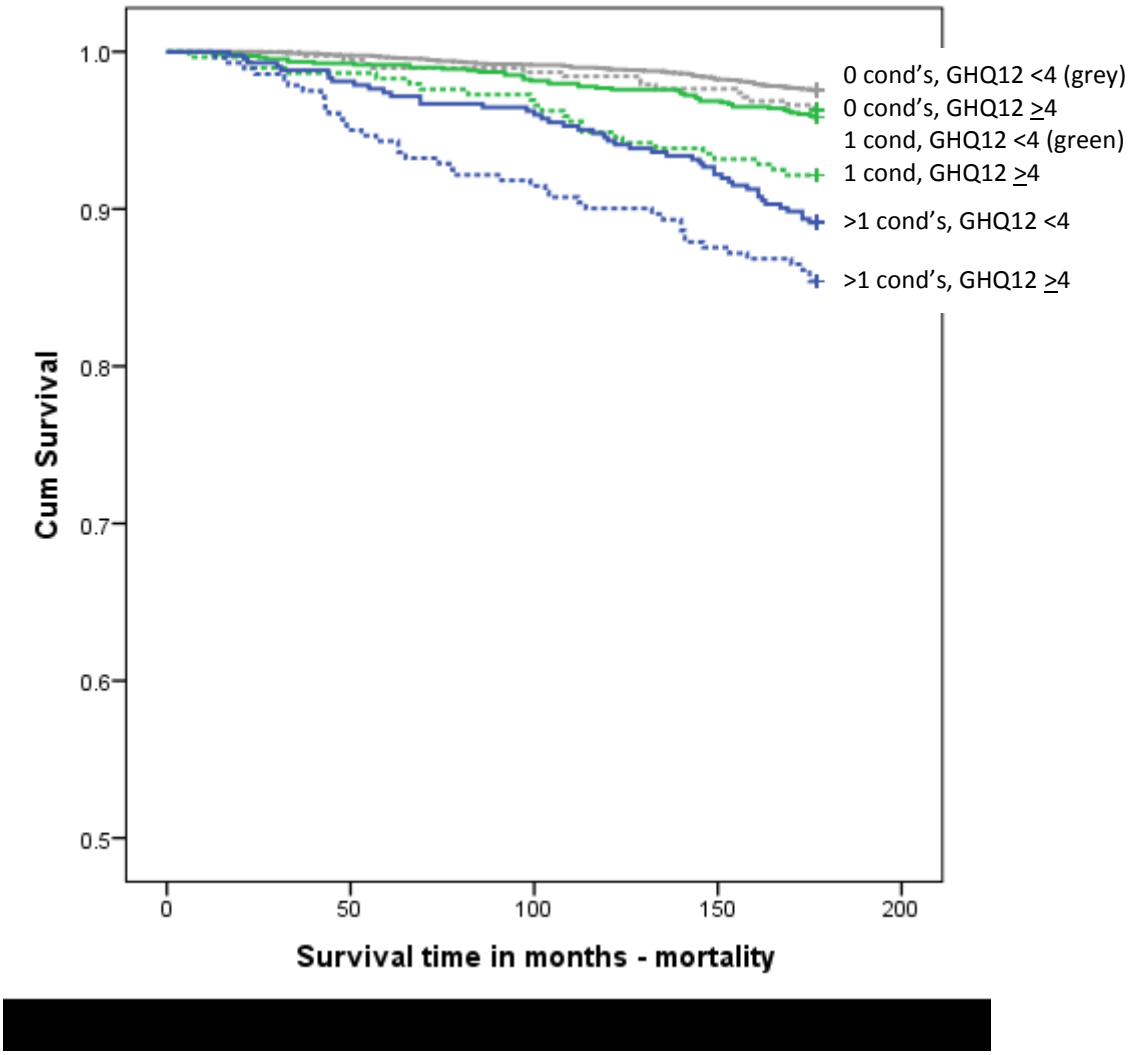
Psychological distress

The third of the mechanisms described above, that impaired psycho-social functioning could itself shorten life, is examined in the next set of survival plots. Using the same approach as above, the association between condition status, GHQ12 score of ≥4 and survival in those aged 16-54 is shown. GHQ12 was the only psycho-social functioning measure included in the 1998 survey; however, its closer association with directly

experienced symptoms of distress arguably makes it the better measure to use in this analysis.

There is a clear additional risk of death associated with having a GHQ12 score of ≥4, evident for those with one condition, and even more so for those with multiple conditions. However, as before, the absolute number of deaths was small overall (most of the group at greatest risk do, after all, survive), so this evidence can only signpost the existence of one possible mechanism among many that accounts for the lower burden of low wellbeing experienced by adults with multiple conditions of retirement age (relative to the working-age counterparts).

Figure 6.28 Kaplan-Meier plot of survival among adults aged 16-54, for the six long-term condition and GHQ12 status groups (14.9 years' follow-up), SHeS 1998-SMR linked data



Note: scale has been truncated to aid interpretation (full scale runs from 0-1).

Conclusion

Collectively these analyses have attempted to reflect, albeit only very partially, some of the ways that living with conditions can be accompanied by psychological, social and physical encroachments of the kinds drawn out extensively in the literature on chronic illness experiences described in Chapter 4.

People with multiple health conditions live with many additional challenges. Some appear to be a distinctive feature of their health status, such as having very low activity levels, high levels of obesity, or low wellbeing, compared to people with fewer

conditions or none. However, when investigated further, it is clear that these challenges are often exacerbated by social deprivation, or vary between age groups, sometimes resulting in a fragmentation of experiences among people with multiple conditions. Low wellbeing functions in this way, so people who experience the combination of both high levels of deprivation and multiple conditions suffer the worst outcomes of all. In contrast, people with multiple conditions living in the least deprived areas fare much better than their more deprived counterparts, and, moreover, they also tend to have better outcomes than people with one condition who live in areas of high deprivation. This pattern is particularly apparent among those aged under 65.

While a quantitative analysis such as this can barely begin to uncover the complexity of experiences that might underpin patterns such as these, a number of mechanisms were tentatively explored. Differential non-response to the wellbeing questions does not appear to have been a factor, nor do variations in the absolute burden of limiting conditions by age group or area deprivation. However, attempts to unpick these experiences suggest that the illness experiences of younger people with multiple conditions are quite distinctive, and feature higher levels of economic insecurity and exclusion from potentially protective social norms, such as home ownership and long-term partnerships. In addition, the experience of living with multiple conditions in conjunction with activity limitations, or social deprivation, or psychological distress at a threshold that might be indicative of a disorder, are all associated with a higher risk of premature mortality. This suggests that, for some people, living with multiple conditions and low wellbeing not only impairs quality of life, it also reduces quantity of life as well.

Chapter 7 Discussion

Introduction

This thesis set out to:

- Quantify the experiences of adults living with multiple conditions in Scotland using the Scottish Health Survey.

By answering the following questions:

- Does the Scottish Health Survey correctly identify people with multiple conditions?
    - And if not, who is missing?
- How do different definitions of multiple conditions affect its prevalence in the population, and across sub-groups?
- How do experiences of people living with multiple conditions vary in the population?

Scotland arguably has some of the most comprehensive estimates of the prevalence of multiple conditions, and of condition-specific patterns within that overall prevalence, of any developed country (e.g. those found in Barnett et al. (2012), McLean et al. (2014), Smith et al. (2014) and Cooper et al. (2015)). And while those data relate to 2007, and did not include west-central Scotland, where some of Scotland's highest levels of poor health are found, the primary aim of this work was not to simply replicate the task of establishing the prevalence of this increasingly important health phenomena with a new dataset. Instead, the aim was to ensure that Scotland's main source of population health data was equipped to make a contribution to this field via its unique potential to provide additional information about the wider life experiences and circumstances of people with multiple conditions, and thereby widen and deepen current knowledge of these aspects, beyond the more biomedical and disease-focused analyses that currently exist. To do this it was necessary to ensure that the survey was correctly identifying people with multiple conditions. Hence the considerable attention paid to this matter in Chapter 5. However, as the approach outlined in Chapter 3 explained, and Chapter 4 demonstrated, I was keen to establish a theoretical grounding for this work, and in doing so, came to understand the problematic nature of what constitutes "correct" or "incorrect" when attempting to

identify health conditions. In a field dominated by very empirically driven analyses (e.g. where availability of data is the predominant criteria used to determine what conditions are included in definitions), I also hoped to make a wider contribution to the way that analyses of quantitative data are approached, by illustrating the potential for plural theoretical perspectives to help shape this process.

This discussion chapter is structured around three themes: measurement, experiences and overall approach (though elements of each feature in all parts). The measurement theme starts by briefly drawing out the headline prevalence figures from Chapter 5 and how they relate to the existing studies of multiple conditions reviewed in Chapter 2. It then reflects more intensely on the process through which the definition arrived at here was developed, drawing on the wider theoretical insights provided in Chapter 4, to outline the key issues that emerged as a consequence. Each stage of the definition process was described in Chapter 5 in some detail. Rather than revisiting the rationale for each decision taken (which are already described in Chapter 5), the intention here is to focus on what might lie behind the information reporting patterns and potential discrepancies that posed the most significant challenges for this work. Finally, their wider implications for the measurement of health in populations are considered.

The experiences theme then considers the results in Chapter 6, again by relating them to the literature in Chapters 2 and 4. When triangulated with the growing, though still somewhat limited, qualitative literature in this field, results such as these have the potential to increase understanding of the mechanisms that might explain why having multiple conditions is associated with such negative outcomes, and why this is particularly the case for some groups. However, Chapter 2 argued that much of the drive to frame analyses and, increasingly, health services and interventions, around the needs of people with multiple conditions has been spurred by the recognition that ill-health is not always a singular experience. The next part of the discussion therefore raises the question of whether the complexities and challenges that accompany the experience of having multiple conditions are in danger of being under-appreciated by treating this set of circumstances as singular concept. In this way, the analysis presented in Chapter 6 is not only a means of illustrating how life experiences are

potentially affected by having multiple conditions, but is also a tool to help critically evaluate the utility of identifying people with multiple conditions in order to explore their outcomes and experiences as distinct from other groups. The final part of the chapter reflects on the approach taken; what it added and what challenges it brought.

How many adults in Scotland have multiple conditions?

Putting the SHeS results in context

This section considers the SHeS results in the context of the broader literature on multiple condition prevalence patterns, based on the systematic reviews by Fortin et al. (2012) and Violan et al. (2014), and the UK prevalence estimates provided by Salisbury et al. (2011) and Barnett et al. (2012). The implications of the comparative results presented in Chapter 5 (comparing SHeS with McLean et al. (2014)) are discussed further below.

Using the definition arrived at in Chapter 5, 24.9% of adults aged 16 and over in the 2008-2011 period had multiple conditions (Chapter 5, Table 5.20). Understandably, every prevalence figure quoted in the literature varies, depending not only on the population studied, but also on the data source and definitions used (of both conditions and of multiplicity). For example, the headline SHeS results were fairly close to the most closely comparable domestic prevalence estimate available (as discussed in Chapter 5), and to the figure cited in Mujica-Mota et al. (2015), derived from the English General Practice Patient Survey (based on self-reported conditions). However, other UK sources, such as Salisbury et al. (2011), cite figures for the population in England aged 18 and over of either 16% or 58%, depending on the conditions included in the definition, thus complicating the extent to which any external comparison of absolute figures can usefully be made.

However, although absolute levels cannot be reliably compared because fundamental differences exist between their sources (Violan et al.'s (2014) systematic review concluded they certainly shouldn't be pooled), a fairly common set of patterns of *relative* differences between key sub-groups have been identified across sources. Establishing whether the SHeS results follow these established relative patterns is an important step in assessing their likely validity. For example, a very notable rise in

prevalence with increasing age is universally reported in general population studies (Fortin et al. 2012) – with an S-shaped curve typically evident as prevalence at older ages plateaus due to ceiling effects, and selective mortality (especially past the age of 75). The SHeS results showed that prevalence increased from 5.4% at age 16-24 to 59.0% for those aged 75 and over (Chapter 5, Table 5.21). The figures for the older age groups presented in Chapter 5 do not have enough granularity to show this S-shape, but additional analyses (data not shown) show that prevalence for those aged 75-84 and 85 and over was indeed very similar (59.5% and 61.1%, respectively), so the plateau reported in the literature was reached here too.

Violan et al. (2014) reported that nine of 14 studies in their review found a higher prevalence of multiple conditions in women than men, and this was the case with the SHeS results: 26.7% in women, 23.0% in men, OR of 1.2 (1.2-1.3) (see Chapter 5, Table 5.21 and ORs in Appendix H Table H5). All of the studies reported in Violan et al. (2014) that investigated SES gradients found multiple conditions prevalence increased as SES declined; again the SHeS results reported in Chapter 5 fit that pattern. And, as Barnett et al. (2012) noted, the deprivation gradient was somewhat confounded by the younger age profile of people living in the most deprived areas, such that the OR associated with having multiple conditions for those in the most deprived SIMD quintile, relative to those in the least, increased from 2.1 (1.9-2.2) to 2.8 (2.5-3.1) after adjustment for age (Appendix H, Table H5). The fact that the SHeS results yield patterns that are also found in analyses derived from systematic reviews, or large-scale UK-based secondary analyses, suggest they have some degree of validity. However, as Chapter 5 suggested, issues still surround certain aspects of their underlying composition and their ability to reflect the experiences of particular sub-groups. The rest of this part of the discussion therefore returns to the very foundations of the definition process adopted – looking at both the approach followed and the outcomes it yielded - and considers the causes and implications of the challenges identified along the way.

Overview of measurement challenges

The results in Chapter 5 confirm what was abundantly clear from the literature covered in Chapter 2 - the number of conditions people have is, of course, entirely dependent on what is counted and the way that counting is done. And this will, in turn, affect the prevalence of *multiple* conditions within single individuals. The various attempts to standardise definitions in this field have focused on aspects such as the duration or chronicity of the conditions being counted, the nature of the data sources used to arrive at such estimates (including how many conditions they need to cover to be sufficient and who provided the information), and the most appropriate thresholds for defining multiplicity. All these aspects needed to be considered for this work, but little of what was explored in this thesis can be said to contribute to their *resolution* - because they are, in many instances, irresolvable in any definitive way. For example, the kind of all-encompassing measure suggested by Le Reste, Nabbe, Manceau et al. (2013) that includes conditions, social vulnerabilities and disease risks might well suit some needs; they clearly think it meets theirs and can transfer across settings (Le Reste et al. 2015). However, for my purposes, this kind of multi-factorial conceptualisation of multiple conditions would have made it impossible to conduct the kind of stratified analyses of experiences presented in Chapter 6. Any attempt to measure multiple conditions must therefore not only address the question "how should it be done?" but also "what is it for?", as Huntley et al. (2012a) suggest, but which is very often absent from much of the literature in this field.

The results in Chapter 5 showed how a number of approaches helped to identify more conditions than the survey's single measure of long-term conditions originally suggested people experience, and from these, identify those with two or more. This process therefore revealed a number of problems with the original data which, as shall be discussed further below, relate not only to the more mechanical aspects of the survey process itself, but also to the complex and contested nature of the underlying health states that were being measured.

Approach adopted

The identification of conditions to include in the measure of multiple conditions formed the core of this work. Chapter 2 ended with two contrasting approaches to disease classification described in Mani et al (2011):

> Hickam's dictum: "patients can have as many diseases as they damn well please" (para. 8)
>
> Occam's razor: "entities are not to be multiplied beyond necessity" (para. 4)

The methodological approach outlined in Chapter 3, and the theoretical insights provided in Chapter 4, about the socially and temporally contextual nature of disease meanings and classifications helped to explain why different approaches such as these might be necessary, and why there isn't a pre-determined and universally applicable set of criteria to resolve this issue. However, those insights also illustrated how the balance of power between the people generally tasked with diagnosing or classifying disease, and those living with it, is rarely even. Therefore, the capacity for patients to do as they please and make these kinds of "choices" – in the way Hickam's dictum suggests - is clearly constrained. In addition to this, and perhaps more importantly, Chapter 4 also described how the various factors that contribute to the framing of disease – and, increasingly, *risk of* disease – collectively undermine the extent to which such matters could genuinely be seen as choices that any individual (clinicians included) freely makes. In contrast, the simplicity suggested by Occam's razor belies a much bigger challenge, namely what constitutes the necessity beyond which entities should not be multiplied, and who should make that decision?

The key principles adopted in this work attempted to address both these issues while also steering a way through two seemingly irreconcilable ontological positions on disease and illness offered by social constructivism and positivism. A wholly constructivist approach would arguably see the question of how many people have multiple conditions as entirely artefactual, or so open to limitless possibilities, that its ascertainment is therefore of questionable value. Viewed through a purely positivist / biomedical lens, arriving at an answer to this is a wholly technical exercise in identifying the appropriate information and enumerating it. The appropriate

information (e.g. the presence of conditions) would be adjudicated largely on the basis of recorded diagnoses, arrived at by an expert's interpretation of directly observable physical signs and diagnostic tests, and where this isn't possible, symptom reporting (preferably supported by external verifications or expert consensus on their significance). In this model, the role for the person actually experiencing a condition is relegated to that of passive recipient of tests and potentially unreliable reporter of symptoms for someone else to interpret. In essence, a condition is what clinicians code and treat as conditions, with no space in that circularity for reflection about why and how such classifications emerge. The very common rejection of studies based on self-reported measures of health status (rather than clinical records) chimes with this approach. On the other hand, as is clear from the literature, and from the results in Chapter 5, self-reported measures *do* have numerous problems. This discussion must therefore also address these problems, and consider whether they justify the widespread critique, or rejection, of self-reported population health data.

Having sketched out some of the more fundamental issues at stake in this work, the following now looks at specific aspects of the process from which the final definition of multiple conditions emerged.

How much detail about conditions is required?

Chapter 5 already described how the process of aggregating condition codes adopted in the survey was thought insufficiently reflective of the health experiences people reported, with too much potential for the existence of multiple conditions to be obscured. Similarly, it established that many conditions had not been mentioned when people were asked to simply report everything *they* thought of as a long-term condition, and concluded that it was important to incorporate additional information in order to better reflect people's experiences.

However, there remained a concern to avoid adding conditions that were much less serious than those typically already reported, either in terms of their likely prognosis or their impact on quality of life, because of the potential to overinflate the measure of multiple conditions (which has parallels with the notion of breaching a necessity boundary, suggested in Occam's razor). This concern was further underlined by the

literature on medicalisation (including that related to psychological distress) and overdiagnosis (of disease risk, in particular) which highlighted the need to be wary of an approach that counted every possible disease marker. The wider validity of the approach was also a concern. In a field dominated by analyses of disease registers or primary care data, and the widespread application of rubrics such as the O'Halloran criteria (O'Halloran et al. 2004) to define chronicity or weighted indices to reflect severity (Diederichs et al. 2012), it would be naïve to assume that the steps I took would not require additional justification in the form of empirical evidence of their impact. In this way, then, the act of constructing the multiple conditions measure was conducted with a dual recognition that while all socio-medical constructions are "*tentative and provisional*" (Rubinstein et al. 2000, p.45), the final measure was also intended to relate to, as far as possible, a set of external realities that, however framed or labeled, have important consequences for the people concerned.

Many of the decisions taken were seemingly uncontroversial. For example, disaggregating the ICD chapters resulted in distinguishing conditions that most analyses of multiple conditions also routinely consider to be separate entities (such as heart conditions and hypertension), albeit with shared aetiologies and, often, treatment protocols. However, the disaggregation also resulted in single musculoskeletal conditions affecting multiple sites (e.g. arthritis in more than one joint) being counted multiply if that was how the participants chose to report them (or the interviewers chose to record them). This level of granularity certainly goes beyond what most clinical data sources reflect, and represents a reframing of – and perhaps challenge to - the traditional bio-medical classification of this kind of condition, by using aspects of its experiential manifestation and not just its underlying pathology. But the reality is that when conditions such as osteoarthritis affect multiple sites in the body, it tends to happen progressively over time, rather than with a sudden, simultaneous onset. Consequently, people's experience of living with the onset of symptoms, the limitations they bring, and the receipt of a diagnosis, is multiple, despite the condition having a singular status in a strict pathological sense. Surgical specialisation also means that someone needing a hip and shoulder replacement will end up seeing different surgeons, so their experience of medical care will also be

multiple rather than singular. However, this approach also represents a level of compromise about data consistency that is not usually well tolerated in survey analyses. As described in Chapter 3, the aggregation was originally implemented, in part, to diminish the impact of variations in participants' reporting styles and interviewers' recording practices, with the data therefore designed to represent the prevalence of conditions at ICD chapter level with a degree of confidence, but with no such guarantee at the level of individual conditions. The way I handled the data therefore resulted in the final measures being able to identify the *existence* of conditions, and multiples of them, but with much less certainty that the nature of those conditions had been recorded in a consistent manner. In their transformed state, these data are not, therefore, well suited to analyses designed to explore specific condition-related patterns within them, such as the kinds of concordant / discordant analyses that are increasingly common in this field (as described in Chapter 2). However, this deficit is, arguably, counterbalanced by the fact that this data source is far better placed to identify the kinds of experience-related patterns presented in Chapter 6, that are absent from most clinical sources. Furthermore, as these adjustments were taken *after* the data were collected, there is nothing to stop other analysts re-instating the aggregation if that suits their purposes.

It is also worth noting that decisions about granularity beset many analyses, especially so in relation to conditions affecting the same body system or with the same underlying biological pathways, and compromises always have to be made. For example, Barnett et al.'s (2012) analysis of Scottish primary care data did not enumerate specific musculoskeletal conditions but instead had a single category of pain disorders based solely on the issue of more than four prescription-only pain medications in the past year. This therefore misses anyone using non-prescription medications to manage a painful condition (e.g. ibuprofen perhaps in conjunction with physiotherapy), while people whose medication covers more than one painful condition (of different causes) cannot be identified. On the other hand, this approach prioritises the symptomatic consequences of conditions that cause pain, which is arguably of greater experiential relevance to the people concerned. These examples illustrate how the kinds of decisions commonly taken with regards to data handling

can sometimes compromise – and sometimes enhance - the data's potential to reflect people's experiences.

The challenge of measuring complex concepts

The overarching, if sometimes unstated, principle of all research that is designed to quantify phenomena (be they social, physical or psychological) is that a sufficiently close fit can be established between what the measures used are *intended* to capture and what they actually *succeed* in capturing. In the absence of this, the whole venture stands on fairly shaky ground, and the different epistemological traditions adopted within and across different disciplinary boundaries clearly reflect the varying degree to which this premise is accepted. The discordance between the prevalence rates based on the unprompted conditions question and the questions that asked directly about named conditions such as hypertension and diabetes, or the variations between people in whether conditions were reported as long-term or as other health problems, perhaps provide examples of measures not yielding the outcomes intended of them.

Most of the analyses of the accuracy of self-reported conditions data discussed in Chapter 2 looked at the agreement between answers to directly prompted survey questions and data from clinical records. However, many of the processes that generate discordances between people's self-reported conditions and their clinical records could not have contributed to the patterns shown in Chapter 5. For example, a commonly voiced concern about self-reported data is that people aren't always told what conditions they have, or haven't understood or don't remember what conditions they've been told about. The discordance patterns uncovered in this analysis could not be blamed on these factors because people *did* report conditions when asked directly about them, so the problem lay with their needing to be prompted to do so, rather than them simply having no knowledge. The root of the problem is likely to be twofold: firstly, the complexity of the question wording (see below), opening up wide scope for people to interpret what was required of them quite variably; and secondly, the fact that the health conditions being asked about themselves have quite fluid meanings or contested statuses. As a reminder, the long-term conditions question in the 2008-2011 surveys asked:

Do you have a long-standing physical or mental condition or disability that has troubled you for at least 12 months, or that is likely to affect you for at least 12 months?

Many of the terms used could have been open to interpretation (as Gooberman-Hill et al. (2003) clearly demonstrated), but I have underlined two (troubled and affect) that can be singled out as particularly problematic. For example, it is unclear whether something that has an intermittent but permanently recurring pattern, such as migraines, should be included, or how a condition that has few symptoms but requires permanent medication should be handled, such as well-controlled diabetes, or indeed a disability whose associated trouble or affect is felt largely as a result of societal constraints, as opposed to any physiologically embodied consequences. The emphasis this question placed on participants' own perceptions of the troubling nature of their conditions is in some ways very welcome, but it will also have contributed to the fact that conditions with few symptoms, such as hypertension or high cholesterol, were the ones found to have the greatest discordance between answers. Hansen et al.'s (2015) work definitely resonates here, especially their finding that patients gave greater priority in their illness accounts to conditions with more invasive symptom burdens, while their doctors gave greater weight to conditions with life-shortening prognoses, highlighting a contrast, perhaps, between the embodied experiences that weigh on the minds of the people living with them, and the negative future consequences associated with illnesses that preoccupy the clinicians charged with their management.

In a similar vein, conditions that straddle the disease / risk boundary, such as high cholesterol, showed quite varied reporting patterns, with the additional complication in this instance that many people don't realise that cholesterol-lowering treatment is long-term rather than temporary, hence the high proportion of people reporting this as an other problem and not as a long-term condition. These results also tie in with the discussion of health experiences in Chapter 4, specifically the quote highlighted from the participant in Lawton et al.'s (2005) study of lay beliefs who voiced suspicions that hypertension was just the latest in a line of fads for doctors to treat. In some cases, variations in condition reporting could also have resulted from decisions people made about their severity, or impact, which led them to not mention conditions like arthritis

or asthma when asked about long-term conditions, but to do so when asked about other problems.

However, the analysis of the nature of people's answers also showed that the overwhelming preponderance of information reported related to named diagnoses, and not to symptoms – and this also applied to the answers to the general question that asked about "problems" as opposed to conditions. It would therefore be too simplistic to characterise the lay-person / clinician divide as one that demarcates these two sets of phenomena as solely relating to what people feel, and what doctors name, or to suggest this is wholly responsible for the reporting patterns seen. Turner's (1987) account of how people relate to their health is instructive here:

> The way in which an individual interprets or understands their disorders will depend, not upon individual whim or fancy, but significantly upon the classifications of illness which are available within a culture and by reference to general cultural values concerning appropriate behaviour. (Turner 1987, p.215).

Furthermore, the idea that simply "improving" the wording, for example by removing some of these more ambiguous terms, would resolve all these issues can be shown to be misplaced. From 2012 onwards the long-term condition question was simplified by removing references to conditions that troubled or affected people, while the term illness was reinstated as well (it had been removed between the 2003 and 2008 surveys). This change only resulted in a two percentage point increase in the proportion reporting a long-term condition and an equal sized decrease in reporting other problems, which is small enough to be within normal sampling variation (Appendix K, Table K1). Similarly, while the proportion of people with doctor diagnosed hypertension who reported it as a long-term condition increased from 28% in 2008-11 to 35% in 2012-2013, signifying some improvement in the question's performance, this still left the majority of cases unreported, and levels of underreported diabetes did not change (see Appendix K, Table K2).

The critical issue attending all these competing perspectives and interpretations is not, therefore, which of them is "correct"; indeed, Gooberman-Hill et al. (2003) suggest that such data should be assessed on the basis of its trustworthiness rather than its truthfulness. Aligned with this approach, arguably what matters is recognising the

plurality of possible interpretations and responses, and appreciating that they have corresponding implications for the collection of information about health. Viewed this way, the results suggest that the wording of the original (and indeed more recently revised) long-term conditions question fails to reflect the fact that perceptions (and consequently, answers) vary because the very concepts being measured do not themselves have fixed, universal meanings. The increasing move to actively treat disease risks will further complicate matters and undermine measures of health conditions that rely on narrowly-formulated questions and ignore the reality of - and variability in - how people experience and understand the conditions they receive diagnoses of, or are treated for. This distinction matters when attempts are made to improve the way such information is collected, otherwise the wrong remedy could be put in place. This is discussed further below.

Contested conditions

Moving away from the difficulties associated with how people interpreted the questions put to them, decisions also had to be made about factors such as obesity, whose status as a condition is highly contested. The results in Chapter 5, in conjunction with the arguments outlined in the case study in Chapter 4, made a strong case for excluding obesity from the condition count. People did not relate to it as a condition, including it did not alter survival trajectories, and significant debate still surrounds its status as a condition versus a risk factor. However, the results in Chapter 6 certainly illustrate the extent to which obesity is a distinctive feature of the lives of people with multiple conditions, and growing evidence (outlined in Chapter 2) suggests it contributes to the risk of acquiring multiple conditions over the lifecourse. Even though the survival analysis of mortality risk showed that obesity was not associated with that particular outcome, it still has the potential to negatively affect the quality of people's lives. For example, as noted in Chapter 6, obesity is strongly associated with shame, with corresponding harmful psychological consequences. It can also negatively affect experiences of health services, if treatments are rationed for people with a BMI above a certain threshold, despite the considerable barriers to weight loss that people with co-existing conditions often face. It is also possible that the nature of the association between obesity and survival has changed over time as its

prevalence has altered (e.g. with onset occurring at earlier points in the lifecourse, or with the higher prevalence of very high BMI now occurring), so these analyses based on outcomes following the 1998 survey might not be replicated with later cohorts. All these possibilities underline the importance of being able to continue monitoring the ways in which people with multiple conditions experience obesity, and whether their outcomes differ notably from those with fewer or no health conditions. These kinds of issues are harder to explore if obesity is included as a condition within overall measures. This underlines the point made above that any measure of multiple conditions needs to take into account its purposes when deciding about its composition.

What conditions are missing?

The discussion so far has focused on what information was collected and how it was incorporated into the multiple conditions measure. A more complex, and arguably more important, issue concerns what was absent. The comparison of the SHeS results with those in McLean et al. (2014) at the end of Chapter 5 suggested the former had two key gaps relating to conditions in older people and mental health conditions. Furthermore, the comparison underlined the considerable extent to which the original, unadjusted multiple conditions measure had under represented people's experiences at all ages, but particularly so for those aged 55-64 and above. However, before considering these issues it is worth reflecting on the nature of the comparison being made. There is always a danger when survey estimates are compared against estimates from other sources, such as clinical data, that the external source is held up to be a gold-standard, presumably free of flaws. Of course, as the above (and Chapter 4) should have demonstrated, the very notion of a gold-standard data source on health conditions is highly questionable, given the highly contextualised nature of the information it could ever contain. While the notion that a single, "true", prevalence of multiple conditions exists in the population is similarly problematic. The primary care data on which the McLean et al. estimates are based only capture the existence of conditions that can be identified via recorded diagnoses or inferred from specific prescription patterns (e.g. the pain medications noted above, or prescriptions for antidepressants). This is an important measure to have, given its direct implications for

GP care demands and likely patterning of demand for secondary care services as well. But it isn't necessarily a complete measure of *all* the health conditions and burdens people live with (by virtue of it being based on a database of diagnosed or treated conditions), nor is it a measure that would necessarily correspond with how people themselves experience their conditions – because there is little space for patients' voices to be reflected in the kinds of routine GP data utilised in epidemiological studies.

Surveys are often promoted as tools for assessing unmet health needs in populations, for example by identifying undiagnosed conditions, thus providing them with a unique potential to provide additional information beyond what is available in primary-care data. As discussed in Chapter 5, this approach is not without its problems. For the most part, problems arise because a survey's capacity to identify undiagnosed conditions is largely limited to those with potentially diagnostic biomarkers that are relatively easy to collect (e.g. by blood pressure readings or blood samples), rather than those requiring more detailed, contextual information and symptom reporting. The biomarker results can be problematic because their clinical significance often occupies contested territory on the risk / disease boundary, especially when there is no wider contextual information available, or repeated measures (hypertension diagnosis in primary care is based on repeated measures, ideally including some taken away from the clinic, rather than on the basis of one set of elevated readings, unless someone has severely raised readings (NICE 2015b)). Chapter 5 showed a prevalence of high cholesterol (using a 5.0 m/mol threshold) suggesting that as much as half the adult population in Scotland could require statins; this isn't a failing of the biomarker or survey *per se*, but of the way in which its information is interpreted. Similarly, mental health disorders are commonly described as hugely under-diagnosed but the potential for surveys to overestimate the extent of this, as discussed in Chapter 4, is very real. Though it must be remembered that, unlike the biomarker data, there is no question that the answers indicating distress highlight troubling and quality of life diminishing symptoms that need to be addressed; the contested issue is whether they are indicative of disorders, as opposed to understandable distress. This potential role for the survey to identify the possible

burden of disease beneath the tip of the iceberg was not, therefore, incorporated into this analysis. Its ability to capture the kinds of information available in primary care sources must therefore be evaluated.

It is possible that comparing the SHeS and the primary care results is akin to comparing apples and pears; they're both measures of population health, but of different populations and of different kinds of health. However, two aspects in which the two sources can be seen to differ most (prevalence of conditions in older people, and of mental health conditions) have very plausible external explanations that do point to significant deficiencies in the survey estimates. Or, at least, suggest that specific caveats need to be placed around their interpretation. Firstly, SHeS is a survey of the household population in Scotland which therefore excludes people in residential care, whose health will in most cases be worse than adults living in their own homes. The primary care data, on the other hand, includes all patients registered with practices, so is better at reflecting the health of all adults, regardless of where they live. Secondly, SHeS only interviews people with full mental capacity to consent to participate and answer on their own account, so this key exclusion will also have contributed to the discrepancies in prevalence for older adults living at home but with impaired cognitive functioning. Similarly, adults of all ages with more than mild learning disabilities would have been excluded from the survey for these same reasons. These two factors, in combination with older survey participants potentially underreporting the extent of their health conditions, make the much higher multiple conditions prevalence in those aged 65 and over provided by McLean et al. perfectly understandable.

Perhaps more worrisome, however, is the survey's underestimation of mental health conditions. Based on the interview data alone, 6.2% of adults had a mental health condition, which increased to 11.9% once people taking psychoactive drugs were included in the measure. Analysis of the prescription data suggested that people taking psychoactive drugs who did not report any mental health conditions were older, on average, than people who reported such conditions. Hence this situation contributes both to the overall lower level of reported mental health conditions, and the

underestimation of conditions among older people. The majority of the psychoactive medications reported were antidepressants, and the majority of mental health conditions reported were depression or anxiety (based on visual inspection of the free-text data - though a wide range of other conditions were also mentioned, such as combat-related PTSD, bipolar disorder, schizophrenia, alcoholism and other addictions). Smith et al. (2014) report a prevalence of depression in adults aged 18 and over in Scotland, based solely on prescription data, of 10.1%. This suggests that, as might be expected, the underestimation of mental health conditions is highly condition specific, with diagnosed depression and anxiety possibly much less affected than other psychiatric diagnoses. For example, dementia was classified as a mental health condition in the McLean et al. analysis, but the sample-frame issues and exclusion criteria described above will have contributed to this being underestimated in SHeS, relative to the primary care data. The sample frame will also have excluded people living in hostels or other types of supported social housing, many of whom have mental health conditions at the more severe end of the diagnostic spectrum, and/or alcohol and other substance abuse disorders (these were also included in the McLean et al. definition). But another important source of the underestimation is likely to be due to non-response to the survey being higher among eligible participants with the poorest health, and especially among those with severe mental distress. Interviewers report that a time-consuming survey involving a stranger coming into the home is often deemed too burdensome a prospect for those with the most extensive health problems, while the sometimes chaotic nature of the lives of people with severe mental distress is an additional factor that makes them harder to find at home and schedule a suitable time to be interviewed. Establishing who doesn't take part in surveys is, by definition, quite difficult. But, data linkage is increasingly being used to compare the health and mortality profiles of survey participants with the general population to aid our understanding of non-response biases. The most appropriate example here is Gorman et al.'s (2014) analysis of alcohol-related hospitalization and mortality, which established that these outcomes were significantly less likely among SHeS participants than the population as a whole, with the gap in outcomes largest for those living in more deprived areas.

The evident discrepancies between SHeS and the primary care data, and their most likely sources, suggest that while it is problematic to treat the primary care data as if it contained the "true" measure of multiple conditions, it certainly appears to contain a more complete measure. The critical issue is what to do with this information. The first obvious point is to ensure that any results based on SHeS clearly highlight what they do and do not represent. That means making explicit the fact that the picture of older people's health presented is only partial, and that the nature of the conditions reflected in the estimates is similarly incomplete. The steps taken to develop the multiple conditions measure in this thesis are also linked to this. This process explicitly acknowledges the complexities of people's health and illness experiences, and the need to consider health from multiple angles, and resulted in a measure of the population's condition burden that was, overall, far closer to that suggested by the primary care data than was initially the case. It is therefore possible to gain a better picture of people's health if additional thought is devoted to the process. The final important point to note is that, despite the fact that some conditions and people are missing from the survey estimates, the information that has been provided still has enormous value. For example, the analyses in Chapter 6, which will be discussed in more detail below, sheds light on just one aspect of the differential experiences of people living with significant health burdens that primary care data could simply never yield. Furthermore, huge potential exists for other analyses to be performed using the survey data, some of which are described in the Conclusion in Chapter 8. In an era of increasing use of routine "big" data it is also incumbent on funders of population surveys to continue to question the value of what they get from such sources and ensure that their full potential is being maximised. As the concluding thoughts in Chapter 8 will touch on, I'm not convinced sufficient attention has been paid to this in recent years, largely due to the heavy demands placed on SHeS to measure "lifestyle" risks and population outcomes. In sum, then, the efforts of the people who contribute their experiences to population surveys – as noted above, often revealing deeply personal information to strangers - should not be diminished or devalued by the presence of known deficiencies in survey processes. Otherwise the collection of that information would, arguably, be unethical.

What changes could be made to improve survey estimates?

Law's (2004) description of the problems associated with the methods utilised in social science research provides a potentially helpful way of framing the challenges revealed by the results presented here: "*while standard methods are extremely good at what they do, they are badly adapted to the study of the ephemeral, the indefinite and the irregular*" (Law 2004, p.4). Long-term conditions are clearly not, by their enduring nature, ephemeral; but I would argue that disease and illness are concepts, or states of being, that certainly have indefinite and irregular characteristics, for all the reasons outlined in Chapter 4. These characteristics, therefore, arguably contribute to the reasons why the identification of health conditions using standardised questionnaires is a particularly problematic venture which requires the kind of multi-stranded approach followed here. This is perhaps especially so because the information is derived from the general population whose myriad different understandings and experiences have to be considered alongside the ontological complexities associated with these concepts. However, it would be remiss to suggest this is a problem solely characteristic of self-reported health data – Bowker and Star's (1999) work on the ICD provides a counter case in point.

One possible conclusion from the suggestion that the diverse meanings and experiences of having health conditions are associated with such complexity is that they will always confound attempts to measure them. However, the unique opportunity that SHeS provides by having disparate sets of information about people's health shows that the potential does exist to bring this together in a demonstrably meaningful way to more fully reflect people's experiences. This is not to say that the questions could not be improved, or the whole process streamlined a little. The small changes introduced from 2012 certainly appear to have made some difference. However, the key conclusion from the work in this thesis must be that people's experience of living with long-term health conditions cannot be fully reflected in a single question, even when it uses a format that gives people space to report their experiences in their own words, as SHeS does, and especially not when it uses a more closed format (for example, the UK's four Censuses ask similar, closed formatted questions (NRS 2015; NISRA 2015; ONS n.d.)).

The most commonly used alternative way of measuring long-term conditions in population surveys is to select a list of conditions thought to be the most relevant or important, based either on their population prevalence, costs or consequences, and to ask people whether they have them, or have been diagnosed by a doctor as having them. The Labour Force Survey (UK Data Service 2015a) and Welsh Health Survey (UK Data Service 2015b) use these methods. This question format saves the considerable cost of collecting and coding free-text information, and effectively resolves the issue of people underreporting conditions like hypertension (if it is included in the list of conditions asked about). However, the main drawback is that the list of conditions needs to be fairly short, otherwise participants will omit information due to the burdensome nature of the task, so its capacity to cover all conditions will be constrained. Switching to use this format in SHeS would require extensive prior consultation about conditions to be included, and concerns would probably have to be allayed if users raised concern that the approach currently in place provides better information. Also, a situation could easily arise where the conditions included solely reflected the priorities of policy makers or service planners, which moves the framing of the information collected even further away from the experiences of people living with conditions. Similarly, careful thought would need to be paid to whether the information sought related only to conditions diagnosed by a clinician (as the SHeS CVD questions currently do), or whether space would also be made for other health problems or symptoms to be reflected. The SHeS other health problems question was perhaps intended to do this, though the evidence presented in Chapter 5 suggests that people's answers were still largely framed in terms of named conditions.

Decisions about surveys' contents obviously have to be made with reference to their key purposes. In effect, SHeS's purposes are twofold. Firstly, its repeated collection of cross-sectional population health data is used to monitor change over time in key health indicators, and social and regional variations in these. As such, its questions must strike the appropriate balance between suiting the needs of the day, and providing continuity of measurement, so changes to key measures have to be very carefully considered. Hopefully the information presented in this thesis can help to

inform such discussions. However, its function as a source of longitudinal data on health outcomes, derived from its use of NHS record linkage, also means that each round of the survey remains a "live", continually evolving, information source, with a shelf-life beyond what is typical for a one-off, cross-sectional survey. The analyses presented here do not, therefore, simply perform the function of highlighting where changes to future questionnaires might be helpful. They also provide examples of retrospective data adjustments that could be applied to the surveys that have already taken place, in order to better reflect people's health experiences and enhance their ongoing potential.

At a minimum, I therefore suggest that the role of the long-term conditions data is examined by the survey's commissioners in Scottish Government, with options for alternative collection formats piloted, following consultations with key data users. The SHeS information, as currently collected, yields a very rich picture of people's health, if used accordingly. But, it's not a hugely efficient method of data collection, both in terms of cost and the time required to collect it, and the question lurks in my mind of whether there is more information than is really necessary. Some of the adjustments made to the multiple conditions estimate were quite marginal, often because the additional information provided related to people who already had multiple conditions. While that information exists it is unethical not to use it. But public money funds this data collection, and a large amount of time is given up by the people who participate. These factors have to be borne in mind when considering what might be lost if some information wasn't collected in the first place. The "other health problems" data pose a particular conundrum. I'm torn between thinking they should be retained, at least until the whole approach to measuring long-term conditions is reviewed, because they clearly provide insights about people's health that are otherwise missing. On the other hand, unless the way that I have used these data in this thesis is more widely adopted (or some other use is identified), it seems very questionable practice to continue collecting this information. The method of handling the "other health problems" data that I developed is probably the most likely to be disputed by more clinically-focused users of the data (because the chronicity or nature of the conditions is less certain than is the case with the other conditions questions).

However, while the survey retains its current format, these data should at least be provided for others to use (they aren't presently in the public dataset, largely because they have never been used - until this thesis - and not because of any concerns for confidentiality). Similarly, the individual condition codes relating to the long-term conditions question should be provided in both their original and aggregated forms. The case for routinely integrating the additional information from the CVD questions into the long-terms conditions measure is compelling, based on the evidence presented in Chapter 5. At the very minimum, the data should be simplified to make their integration by secondary analysts more straightforward. Finally, feedback on some of the coding discrepancies identified in this process has been provided to the survey contractors, for example to highlight the need for editors to be consistent in assigning separate codes to depression and anxiety (this was not always the case). Further briefing of interviewers about how to input data when people mention multiple conditions was also recommended, as was the possibility of introducing a programme prompt so that any instances of the word "and" being inputted trigger a flag to check that multiple conditions are being correctly recorded.

What is the value of identifying people with multiple conditions?

Introduction

The discussion has so far focused on the measurement of the individual conditions that underpinned the measure of multiple conditions, rather than on the value of conceptualising multiple conditions as a collective status of interest. These concepts are, of course, related, because the degree of granularity that exists in the underlying data will affect the prevalence of multiple conditions (as the ungrouping of conditions grouped under ICD chapter headings demonstrated). Hence the decisions about how much granularity was appropriate were also taken with the ultimate purpose – to identify people with *multiple* conditions – in mind. However, the question of how to conceptualise this phenomenon is far more complex, as reflected in the large volume of literature devoted to this topic (outlined in Chapter 2).

As noted in the introduction, the discussion that now follows of the analyses of experiences presented in Chapter 6 is primarily intended to serve as a framework for

assessing the value of identifying a group of people with multiple conditions. Valderas et al. (2009, p.357) suggest the following criteria could be used to evaluate the utility of definitions or measures of multiple conditions:

> the value of a given construct lies in its ability to explain a particular phenomenon of interest within the domains of (1) clinical care, (2) epidemiology, or (3) health services planning and financing.

Leaving aside the issue of whether any single measure can fully *explain* a phenomenon without recourse to other sources of evidence, these criteria could provide a useful framework for assessing the measure arrived at in Chapter 5, but with the term "explain" perhaps better replaced by "increase understanding of". Applied in this way, then, the question would be: in what ways does grouping people according to the number of conditions they have increase understanding of population wellbeing patterns? With wellbeing treated as a phenomenon of interest in epidemiology and in wider public policy. However, a more challenging – but potentially more pertinent - framing would be: in what ways does analysing wellbeing increase understanding of the experiences of people with multiple conditions? This reversal of the assessment criteria opens the potential for the value of the construct to be challenged not because it reveals little about an outcome of interest, but because what it reveals presents a challenge to the very construct itself. The following discussion of the wellbeing patterns in Chapter 6 therefore attempts to address both these questions. This approach reflects the aspiration set out in the methodology section of Chapter 3 - to treat all such constructs as potentially fallible, without necessarily undermining their value to a point that they are no longer deemed useful.

What do the experiences of people with multiple conditions reveal about wellbeing in the population?

The results in Chapter 6 represent the most comprehensive analysis of the association between wellbeing (measured via WEMWBS) and multiple conditions conducted to date. However, as the literature in Chapter 2 made clear, the association between having multiple conditions and poor psycho-social functioning, using measures such as health-related quality of life (HRQoL), has been explored previously (Fortin et al. 2004; Huntley et al. 2012b; Mujita-Moja et al. 2015), including in Scotland, using the

2003 SHeS (Lawson et al. 2013). While wellbeing and HRQoL are different constructs (Schrank et al. 2015), the key finding that outcomes were worst for people with multiple conditions of working-age living in deprived areas was common to both this analysis of wellbeing and Lawson et al.'s (2013) analysis of HRQoL. Similarly, the finding that the association between condition status and wellbeing was much less pronounced among older adults replicates the patterns seen in Lawson et al.'s (2013) and Mujita-Moja's (2015) HRQoL analyses, with the latter concluding that this might be explained by "*lower expectations of health in older age or a greater ability to adapt to lifestyle changes imposed by adverse health events*" (p.915). In contrast, the deprivation gradient in HRQoL reported in Lawson et al.'s (2013) results did not follow a uniform pattern (the two most deprived quintiles had similar results, as did the two least), whereas the increase in levels of low wellbeing shown in Chapter 6 (Figure 6.13) followed a stepwise pattern across each quintile. This difference might have resulted from the differences in the underlying multiple condition measures used (Lawson et al. used the grouped SHeS long-term conditions measure which, as demonstrated in this thesis, disproportionately underestimates multiple conditions among the working-age population in deprived areas), though it is also possible that wellbeing and HRQoL have different social distributions in relation to condition status (unfortunately SHeS has never measured both simultaneously). Mujica-Moja et al. (2015) adjusted for area deprivation in their analyses but did not present any stratified results or discussion of the impact of socio-economic context on HRQoL.

Moving beyond what has already been demonstrated in the literature, the size of the sample available for the analyses conducted in this thesis made it possible to explore some of the patterns identified in Lawson et al. (2013) with greater precision, and to investigate some of the potential mechanisms they suggested might account for those patterns, such as greater levels of functional impairment among younger adults. Lawson et al. stated that the survey did not measure severity. However, the analysis of activity limitations presented in Chapter 6, which captures an aspect of severity, demonstrated that integrating this aspect adds important insights. Principally, it showed that the very clear differences in wellbeing by condition number were only really evident among people living with multiple conditions that included activity-

limitations. Similarly, the deprivation gradient in low wellbeing was much more pronounced among people with activity limitations than those with non-limiting conditions. Finally, the social inequality in the prevalence of multiple conditions illustrated in Chapter 5 is also, on closer inspection, accounted for by inequalities in the distribution of multiple conditions in the presence of activity limitations. These patterns suggest that it is not the sheer fact of having more than one condition that shapes wellbeing, but that what matters is the much higher likelihood that having multiple conditions is accompanied by activity limitations (three-quarters of people with multiple conditions also reported activity limitations compared with a third of those with one condition). This was also supported by the results of the additional analyses of survival in Chapter 6. The challenges wrought by having multiple conditions are not, therefore, simply due to the complexity of managing or living with more than one condition, but due to the increasing extent to which they encroach on people's functional capabilities.

However, activity limitations alone clearly cannot account for the very notable variations in wellbeing by age and by deprivation among those with multiple conditions, because the results in Figure 6.22 showed that activity limitations were as likely to be reported by younger people with multiple conditions (who had the highest levels of low wellbeing) as they were by older people (with the lowest levels). As Chapter 6 has already noted, it seems likely that the psycho-social meanings and consequences of having activity limitations while still of working-age are worse than they are when experienced at an older age, so this simple measure of their existence has failed to capture that aspect. Identifying some of the ways in which the consequences of having multiple conditions differed between those still of working-age and those of post-retirement age helped to provide some evidence that this is indeed the case. One example of this is the greater extent to which the lives of people with multiple conditions aged under 65 differed from those of their counterparts with fewer or no health conditions in terms of their increased level of contact with the welfare state, and lower levels of home ownership and partnership formation. The possibility of a healthier survivor effect, illustrated by the survival analysis that showed how the contextual factors of severity, distress and deprivation - when combined with

living with multiple conditions - were all associated with higher mortality risks, will also be a factor.

It is important to note, though, that the outcomes for older people with multiple conditions were not uniformly positive, and they were still socially patterned, with the most deprived adults in this group having higher levels of low wellbeing than their least deprived counterparts (as was found by von dem Knesebeck et al. (2015)). Similarly, Ong et al.'s (2014) study of resilience and multiple conditions, which was conducted almost exclusively among people aged 65 and over, described how couple relationships and wider social and family networks were put under strain (including physical separation following one partner's move to a care home) as a consequence of worsening health. So the results presented in Chapter 6 must not give the impression that low wellbeing is not a feature of the lives of older people with multiple conditions. The point is that as a group, in relative terms, people aged 65 and over with multiple conditions had better outcomes than those aged 16-64 with multiple conditions.

The insights offered by Hurd Clarke & Bennett (2013) are useful here. As noted in Chapter 4, their participants often accommodated and framed their illness experiences as inevitable consequences of ageing, sometimes drawing active comparisons with their less healthy counterparts in order to contextualise their own experiences (a phenomenon described as a "*poor dear hierarchy*" (p.354)). At their age, most of their friends and other social contacts had some degree of ill-health so the comparisons they made drew on a spectrum of similar experiences. In contrast, the extended social networks of younger people with multiple conditions will be far more likely to include a majority of people with few or no health problems, even if social sorting has resulted in their closest contacts having similarly poor levels of health. The people with multiple conditions interviewed by Duguay et al. (2014) – who were aged 37-66 years – described their deteriorating health as a form of premature ageing, which supports this notion that having multiple conditions in younger adulthood is a socially distinctive, and indeed isolating, experience.

People with multiple conditions, especially those aged under 65, and those living in areas of high deprivation, clearly experience a high burden of low wellbeing. It is

possible that this is simply indicative of the high burden of mental health conditions experienced by people with multiple conditions of working-age that sources such as McLean et al. (2014) have revealed, but that population survey data struggle to reflect. Low wellbeing does, after all, appear to have a close correlation with diagnosable mental illness (Stewart-Brown et al. 2015), and many of the aspects covered by the WEMWBS items are potential symptoms of depression. Regardless of its designation, the arguably more challenging issue is how to improve the wellbeing of people within this group. It is clear from sources such as O'Brien et al. (2011 & 2014) that the scope to do this lies almost exclusively beyond the realms of what health services can deliver. For example, both studies illustrate how the boundaries between what constitutes a health problem and what might more appropriately be seen as a social or economic issue are very unclear for people who live with the complex combination of multiple health conditions and deprivation, especially if mental health problems are also present. These kinds of insights, when coupled with the results of this analysis of wellbeing suggest that people with multiple conditions display highly heterogeneous patterns of outcomes and experiences, with deprivation a fundamentally important determinant of these. This, therefore, leads to the question of what such patterns suggest about the value of grouping people solely on the basis of their condition count.

What do wellbeing patterns reveal about the experiences of people with multiple conditions?

A number of aspects of the findings in Chapter 6 suggest that the group of people with multiple conditions has highly heterogeneous characteristics. Firstly, the individual components of the scale that reflect low wellbeing, and the overall summary measure, both showed a graded relationship with condition numbers, with increasingly worse outcomes evident as condition numbers increased (when grouped from none to five or more; Figures 6.7, 6.8 and 6.10). No individual item (or the summary measure) demonstrated a pattern which clearly demarcated a particular threshold above which outcomes were notably worse than they had been for the previous group (though the overall pattern was curvilinear due to a slight upturn in negative outcomes evident when reaching the five or more group, which is itself a composite group including people with up to nine identified conditions). Therefore, the fact that low wellbeing

was notably higher among people with multiple conditions than those with one or no conditions was simply an arithmetic function of the much lower levels of wellbeing among people with the highest number of conditions, rather than the breaching of a critical threshold beyond which experiences were markedly different. The grouping of people according to whether they have more than one condition could, for this outcome at least, be said to be somewhat arbitrary, if this empirical aspect of the measure was the sole criterion determining its conceptualisation. And it could certainly be argued that the very negative experiences of those with the highest number of conditions are underrepresented in subsequent analyses using this threshold. However, while it is clear that outcomes continue to deteriorate as conditions numbers increase, the population prevalence of having higher numbers of conditions also drops markedly, which creates analytic challenges due to small sample sizes. Creating a summary measure that aggregates all those with more than one condition might therefore be blunt, but it is clearly expedient; the other complexities and increased illness work (of the kind described by Corbin & Strauss (1985) and discussed in Chapter 4) that are clearly associated with having more than one condition are also important considerations when determining how this status should be conceptualised, beyond the empirical patterns demonstrated here. As Chapter 4 illustrated, few concepts in this field can be genuinely demonstrated to be free of arbitrary, or at least, contingent, considerations. The important point is to recognise that all such constructs have these characteristics, and to use this recognition to avoid them becoming overly reified.

Secondly, however, integrating a measure of severity revealed how the combined presence of activity limitations and multiple conditions appeared to be a key factor differentiating wellbeing outcomes, rather than just multiplicity *per se*. The literature review in Chapter 2 noted a number of sources that drew similar conclusions about the limitations of measures that solely focus on the number of conditions people have, without also taking into account their wider impact on people's lives, with functional limitations often cited as an important factor to consider (Valderas et al. 2009; Mercer et al. 2009; Diederichs et al. 2011; Beard & Bloom 2014; Chrischilles et al. 2014). The strength of the data source used in this thesis is that it enabled people to make their

own judgements about the extent of their limitations, though the main weakness, as already noted in Chapter 6, is that this was only asked about in relation to long-term conditions that were reported without prompting. A more fundamental weakness is the absence of further details about these limitations, for example in what domains of people's lives they were most acutely felt, or how many limitations people faced. Furthermore, in light of the very different outcomes experienced by younger people with multiple conditions, there would also be value in attempting to measure the extent to which people's aspirations are constrained, as well as their daily functional capacities.

Thirdly, the age-related patterns in wellbeing, and also the age by deprivation-related patterns in overall prevalence of multiple conditions, suggest the possibility that this is a construct whose meaning, and certainly whose consequences, vary over the lifecourse. As noted in Chapter 2, Fortin et al. (2012) suggest that a different threshold might be of value to better differentiate the experiences of older people (most of whom have at least two conditions). However, when it comes to differentiating between *outcomes* among people with multiple conditions, using a threshold of three or more (across the board or just for those aged 65 and over) adds little value. As Figure J1 in Appendix J shows, levels of low wellbeing are even higher among those aged 35-64 when this higher condition threshold is applied, while the figures for those aged 65 and above differ only marginally, and the sample size for those aged 16-34 becomes too small to be meaningfully representative.

Finally, it was clearly the case that within each area deprivation quintile, low wellbeing was far higher among people with multiple conditions than among those with one or none. However, when the quintiles were compared, people with multiple conditions living in the least deprived areas had better outcomes than their more deprived counterparts with lower reported condition burdens. This of course raises the possibility that some people with one condition living in the most deprived areas had their condition burden underestimated, perhaps due to undisclosed or undiagnosed mental health conditions. However, the twofold increase in low wellbeing seen between people with one conditions and those with multiple conditions living in the

most deprived areas suggests that misclassification was probably not responsible (outcomes would be more similar if the one condition group contained a lot of people who actually had multiple conditions).

The conceptual implications of heterogeneous experiences

As noted above, questioning the conceptualisation of multiple conditions in this way does not necessarily need to yield the conclusion that it is a meaningless categorisation. Rather, the point is to identify more clearly what it does and does not mean, where it adds value and where it does not, and to use these insights to further shape both its conceptualisation and its application. Viewed from a critical realist perspective, multiple conditions is clearly a socio-medical categorisation that now exists, as evidenced by its proliferation as a research subject, its increasing use in policy circles, and in clinical practice. But it is also, for many people, a social reality that they experience directly, either via their understanding or interpretation of the multiple diagnostic labels they have been given, or through their different symptomatic manifestations, or via the increasing treatment burdens and clinical encounters they impose. They might rarely (if ever) use a term like multimorbidity, but they definitely inhabit a world in which poor health is experienced as a multiple rather than singular phenomenon. Simply highlighting the more socially constructed and contingent aspects of a concept such as multiple conditions without also recognising the extent to which it can help illuminate aspects of the lived realities of the challenges people face when confronted with increasing numbers of conditions, and the functional limitations that they bring, arguably devalues those very experiences.

Collectively, the four aspects outlined in the preceding section highlight the fact that a narrow, biomedically-focused measure of health conditions can never fully reflect the entirety of the life experiences and challenges that are relevant to understanding people's wider outcomes. Put more simply, health-related outcomes cannot be understood solely in terms of health-related inputs. The social context also matters, and in fact, in some circumstances, arguably matters more, especially if social context is taken to mean not only the socio-structural environments in which people live, but also the social functions they have the capacity to enjoy. However, as an organising

heuristic, identifying people with multiple conditions could at the very least be viewed as a useful starting point from which to further explore experiences and outcomes. This is because, regardless of how people choose to frame and interpret their health experiences, living with poor health is an important reality of many people's lives and it confers significant negative consequences. The key is remembering that it is not the *only* important reality of people's lives. Viewed like this, its limitations as a categorisation are therefore most acute when conditions are viewed as the sole characteristic of interest, with no further considerations paid to other key contextual information. This point could be criticised as obvious or platitudinous, were it not for the fact that a large amount of the published research in this field uses sources that have little or no information about the socio-economic context of its subjects, or of the ways in which conditions impinge on their activities, and many are based on very partial data about health conditions – with mental health conditions often completely absent.

Conclusion

This discussion has attempted to address the issues of both measurement and conceptualisation in relation to the phenomenon of having multiple long-term health conditions. It reflected the distinctive approach taken in the thesis to use a broad set of theoretical insights to help guide measurement decisions, underlined by a concern to follow a critical realist-informed approach that treated all constructs as fallible, but not necessarily flawed beyond utility. The strengths and limitations of this approach are considered further in the next chapter, which provides the overall conclusion to this thesis, and also includes suggestions for where this work could be taken next.

With their focus on the individual building blocks that underlie the multiple conditions measure, the problems identified with, and recommendations made for improving, the measurement of individual conditions could be seen as distinct from those relating to the issues associated with measuring conditions in aggregate. However, as already noted, the inter-relationships and boundaries between conditions and how people experience them, and the questions relating to where risks end and conditions begin, are important issues that have consequences for the way that

conditions are conceptualised both individually and collectively. In much the same way, measurement and conceptualisation should not really be seen as entirely distinct exercises, but are, of course, two linked dimensions of one much broader activity. For example, the decision about whether to conceptualise multimorbidity as an entity relating solely to health conditions, or to follow the more expansive definitions offered by some in this field – such as Le Reste et al.'s (2013), or Mercer et al.'s (2009) suggestion to consider "*existential and spiritual distress*" (p.79) as morbidities - has obvious associated measurement consequences.

However, decisions about conceptualisation clearly have more than just measurement consequences; the analytic potential offered by different conceptualisations of multiple conditions is also an important consideration. The literature review in Chapter 2 devoted considerable attention to the definitional wrangling that has accompanied research in this field to date, and noted studies that highlighted the need to draw clear connections between the nature of how measures are defined and the ultimate purposes to which they are put (e.g. Valderas et al. 2009; Diederichs et al. 2011; Hughes et al. 2012). One aspect of the conceptualisation of multiple conditions that has been somewhat under-developed in this thesis is the question of what the measure is intended for (beyond just descriptive epidemiology of this phenomenon). Furthermore, three distinct trends in the literature suggest that the work presented here, and its creation of a *single* measure of multiple conditions, could be criticised for being too conceptually narrow. These are: the increasing use of more complex analytical and conceptual frameworks in this field (e.g. Schaink et al. 2012; Grembowski et al. 2014); the move towards using data reduction techniques to identify clusters of patterns in conditions among those with multiple conditions (Prados-Torres et al. 2014); and the recognition that factors such as functional capacity are a critically important aspect of people's illness experiences and ultimate outcomes (Beard & Bloom 2014; Chrischilles et al. 2014). This issue is explored further as part of the recommendations for future directions discussed in the next chapter.

Chapter 8 Conclusion

Introduction

The book from which the title for this thesis was borrowed – C. L. R. James's *Beyond a Boundary* – is prefaced with the following observation:

> *What do they know of cricket who only cricket know?* To answer involves ideas as well as facts. (James 1963, p.n.p., emphasis in the original).

Although clearly relating to a different field (figuratively and literally), the approach it suggests has a number of resonances with the work presented in this thesis. For example, its concern to integrate theory and data, and its use of perspectives that lie beyond the boundaries typically occupied by epidemiological analyses. This concluding chapter starts by drawing out some of the main strengths and limitations of this approach. This is followed by a discussion of potential new avenues that could be explored to address some of the limitations raised, and to further increase understanding of the lives of people with multiple conditions. It includes, for example, suggestions for new ways of analysing the existing data, or for collecting new data on aspects that could potentially be collected in future studies, either using population surveys, or via other, more methodologically diverse, study designs.

Strengths and limitations of the approach followed

Introduction

This section will not repeat the discussions of the strengths and limitations of the data source that were covered in Chapter 3. Similarly, the well-rehearsed sources of bias that attend all population health surveys were already discussed in Chapter 7 in relation to the kinds of information and people that were likely to be missing due to non-response to the survey as a whole, or parts of it. Finally, the various problems identified with measuring people's conditions, also outlined in Chapter 7, do not need further discussion here. Instead the focus now turns to the strengths and weaknesses associated with the overarching methodological approach adopted in this thesis - its attempt to integrate theory and data and, in so doing, expose the process of measuring and conceptualising multiple conditions to a level of scrutiny not always typical of

quantitative epidemiological analyses. The discussion of the value of what the approach added has been integrated into the consideration of its strengths.

Strengths

One way to evaluate the strengths of an approach is to identify examples where it resulted in beneficial outcomes that might otherwise not have occurred, or helped to avoid problems that might have arisen. In this way, the value added by an approach can be identified. In this case, for example, the insights gained from reviewing the literature on psychiatric nosology and the problems associated with population survey measures of distress, coupled with the wider literature on medicalisation and overdiagnosis, helped to avoid creating a measure of multiple conditions that was over-inflated by disease risks of questionable value and markers of transient, everyday stresses of life. I know that previous analyses I have conducted of SHeS (and other similar data) have paid much less attention to these issues, and that my approach will, in future, be far more cautious as a result of what I learned through this process.

This approach provided a framework for thinking more broadly about the measurement of health conditions in terms that didn't presume a definitive "correct" answer was out there waiting to be captured using a standardised format that could be applied to all people. Instead, it accepted that people's interpretations of questions about their health will differ for a variety of reasons, not all of which were the consequence of defective survey measures that could be addressed by small changes to wording. This didn't mean that recommendations for improvements to the survey questions were deemed irrelevant, but rather the emphasis was placed on ways to re-design the questions to better reflect the diversity of understandings and experiences that exist in the population.

The approach also provided a space for the accounts provided directly by the people interviewed to be more fully integrated into the analysis. This had practical benefits in terms of helping to create a more comprehensive measure, but it was also, arguably, a more ethical approach given that it drew on a considerable amount of information that had been provided over the years but never used. It did this by working from the presumption that all the additional information provided was potentially of value,

rather than treating it as inconvenient noise within the data (the use of the disaggregated conditions is an illustration of this). The term *potentially of value* is important here as there was also an explicit acknowledgement that some of the information provided would not be valuable and could, in fact, cause harm if it were to result in diluting the experiences of people whose health burdens were at the more severe end of the spectrum (a caution raised by Aronowitz (2009)). The value of illness accounts, as eloquently illustrated by Frank (1995) in *The Wounded Story Teller*, was influential in the decision to use the assessments of self-rated health to help determine whether the "other" health problems people reported should be included in the multiple conditions measure (Turner's (1987) work was also valuable in this respect). However, a balance clearly needed to be struck between being overly inclusive and too restrictive when identifying conditions to be included. Coupling these accounts with survival analysis to give it some grounding in a directly observable outcome (death) therefore provided a useful means to help arbitrate on such matters and to demonstrate the wider validity of the measurement decisions.

Moving on from the measurement and conceptualisation aspects of this work, another strength was, arguably, its attempt to move beyond the mere identification of patterns in outcomes by condition number. The discussion of critical realism in Chapter 3 described the ways in which it had influenced the work presented in this thesis, and outlined its arguments about the need to identify mechanisms potentially underlying associations between phenomena. As Sayer suggests: "*patterns of events, be they regular or irregular,* are not self-explanatory, but must be explained by reference to what produces them" (Sayer 1992, cited in Dunn 2012 p.29, emphasis added by Dunn). The identification of potential mechanisms to explain the different patterns in wellbeing among people with multiple conditions across different age groups, and by extension, to understand why low wellbeing was much more a feature of having multiple conditions while of working age was, therefore, my attempt to engage with this approach. Citing Sayer, Dunn (2012) described this process as follows:

> The "mode of inference" by which "events are explained by postulating (and identifying) mechanisms which are capable of producing them is called '*retroduction*'" (Sayer 1992, cited in Dunn 2012, p.30, emphasis in original).

The mechanisms explored were quite broadly drawn. They included the potential that people whose lives feature both multiple conditions and additional contextual challenges (such as activity limitations, deprivation or psychological distress) die sooner than those who don't experience these additional challenges, thus contributing to a healthier survivor effect. Another was the potential that the higher levels of low wellbeing found among people living with multiple conditions while still of working age were related to their greater likelihood of economic marginalisation (only half of this group were economically active) and exclusion from other social norms, such as long-term partnerships and home ownership. The process of identifying mechanisms is akin to peeling an onion, and the layers explored here represent only a small snapshot of the kinds of dynamics that might have produced the patterns observed. The point was to explore the potential to use the data to think in this way. There are, of course, major limitations in using cross-sectional data to draw conclusions about the nature of associations between phenomena (some of which are discussed further below). However, the identification of mechanisms such as these is not meant to be a definitive exercise, but should instead lay the foundations for further investigations using approaches better suited to this purpose (as also discussed below).

Limitations

The decision to use wellbeing as a marker of the wider contextual challenges that people with multiple conditions experience, and to reject the use of GHQ12 to identify psychiatric morbidity 'caseness', has limitations as well as the strengths noted above. For example, it is possible that it created an artificial partition between conditions and wellbeing that, based on the work reported in O'Brien (2014), has little grounding in terms of the way that people live with these experiences, and missed an opportunity to address the underestimation of mental distress that was clearly evident in the data. The question of what should be counted as "normal" and "abnormal" distress lies at the heart of the tensions that have run through psychiatric nosology for decades, as discussed in Chapter 4. This analysis could not, therefore, reasonably have been expected to resolve it in a way that avoided all limitations. Indeed, in an editorial discussing the results of Smith et al.'s (2014) analysis of the co-occurrence of depression and multimorbidity (based on the same source as Barnett et al. (2012)),

O'Dowd (2014) describes the difficulties associated with establishing whether symptoms of "*unhappiness, pain, and impaired function*" reported by people with physical conditions warrant an additional diagnosis of depression, or whether they instead reflect "*a form of grief over the progressive loss of function that chronic illness brings about*" (p.e1319). The discussion then goes on to describe the association between deprivation and the increased prevalence of these conditions and symptoms, suggesting that "*Summoning the personal resources required for daily living in deprived areas takes its toll and is expressed as a more painful existence than for those living in better circumstances*" (p.e1319). An obvious solution to the issue of whether to classify low wellbeing or high psychological distress as conditions that could contribute to the multiple conditions definition would have been to create two measures and assess their utility. This could form the basis of future work.

Another potential limitation was the fact that the analysis of wellbeing patterns, and the attempt to identify potential mechanisms underlying them, focused on very proximally-located phenomena. This is partly a function of the nature of the available data, though as the discussion of risks at the start of Chapter 6 illustrated, only having access to proximal measures (such as smoking prevalence) does not necessarily mean that these have to be framed or interpreted solely in those terms. However, as the literature review in Chapter 2 briefly touched on, the rise of multiple conditions can, in part, be attributed to the global drivers of NCD prevalence, and these are largely (or even wholly) a consequence of mechanisms operating within the political and economic spheres. Much further thought (and analysis) is therefore required to elucidate the pathways operating between these highly distal (and complex) factors and the chain of intervening objects that result in their ultimate manifestations in the lives of people with multiple conditions. Some question the value of approaches that attempt to identify such pathways, for example, Collins et al. (2015) suggest it draws attention away from the fundamental political drivers of health inequalities and risks misidentifying the appropriate actions to address them. However, acknowledging the fact that the drivers are very distally located doesn't have to be incompatible with attempts to further understanding of how these chains of complex interrelated

phenomena ultimately come to result in physical and psychological damage to people (Macintyre 2007). These kinds of insights could then be used to identify and implement at least mitigating, if not necessarily preventative, actions (Douglas 2015).

No analysis of health inequality is complete without a critique of its measures of social position and the problems associated with adequately capturing this aspect of people's lives (Galobardes et al. 2007). The measure used in this thesis, the Scottish Index of Multiple Deprivation, is an area-based, as opposed to individual-level, measure of socio-economic context. Consequently, it is only a proxy measure of a person's social position (though area is an important context too (Pearce et al. 2015)). Not all of the people living in the most deprived areas will themselves be socially disadvantaged by any other standard measures, while many socially disadvantaged people do not live in an area with these characteristics (this is a particular problem in rural parts of Scotland Fischbacher (2012)). The choice to use SIMD was quite deliberate. It has no missing data, unlike the survey's measures of household income and occupation-based social class, and is the most used measure of disadvantage in Scotland for both research and policy. As Fischbacher (2012) outlines, all of the main initiatives to reduce health inequalities or improve outcomes among the most disadvantaged people use this measure to target resources. However, the potentially negative consequences of this can be illustrated by the fact that the majority of people with multiple conditions and low wellbeing did not live in the most deprived SIMD quintile (data not shown), hence targeting this group solely by means of their geographic location will not be effective. Hence these limitations must be aired, and the recommendations for future work include suggestions for incorporating some of the survey's other measures of disadvantage into analyses, as well as ideas for other measures that could be useful.

The final limitation to note relates less to the *approach* that was followed and is more to do with the overall balance achieved between aspects relating to measurement and those relating to conceptualisation. Ultimately, more consideration was devoted to what conditions to include than to the more fundamental question of what the measure was ultimately for. However, the outline of potential future developments presented below is an attempt to address this by suggesting applications to which the

new measure could be put as well as refinements to its construction that might sharpen its purpose.

Where can this research go next?

The above discussion of strengths highlighted its use of theoretically diverse approaches to conceptualising disease and illness to help guide the definition process. However, as the discussion in Chapter 7 touched on, a measure of health constructed around conditions (as opposed to symptoms or functional limitations) is still, ultimately, a very biomedically-focused conceptualisation of health experiences. There are clear reasons why knowing how many people in a population live with multiple conditions is of value, how this varies by social group, and what negative consequences this status brings. This is so even if the criteria used to determine whether someone has a condition, or multiples of them, are fallible (so long as this fallibility is acknowledged). Such reasons include not just the sheer volume of illness work and cascade of symptoms that can result from multiple diagnoses, and the fact that people do not necessarily experience their conditions as discrete entities. There is also the consideration that having multiple conditions will bring challenges above and beyond the sheer fact of their aggregation, such as unhelpful drug interactions, unrelated symptoms that exacerbate each other, or the stress of managing conflicting or contradictory treatment advice. However, there remains a value in ensuring that groupings such as these do not become essentialised (i.e. treated as if they had singular, fixed characteristics), resulting in the heterogeneity of their composition and experiences being lost in the process. Population data have a unique advantage over clinical sources in that they can draw out these heterogeneities far more expansively by drawing on wider characteristics that capture aspects of people's lived experiences and social, economic and cultural circumstances. Chapter 6 opened by briefly locating wellbeing within the wider context of other challenges that are often linked with health outcomes, such as smoking, high BMI, low activity levels and poor diet. As discussed then, these kinds of challenges can often acquire additional significance in the context of existing health problems, either because they exacerbate symptoms, or because failing to address them (either in the past or the present) can provoke stressful feelings of shame or failure, or result in the withholding of care (e.g. BMI restrictions

on surgery). Hence their significance as potentially important markers of other complexities that people with multiple conditions might face, sometimes disproportionately so, relative to people with better health.

The literature reviewed in Chapter 2 included a number of studies containing proposals for frameworks for approaching this topic that better reflect the complexity of circumstances people with multiple conditions face (e.g. Schaink et al. 2012; Grembowski et al. 2014), or suggestions of definitions that encompass many of these aspects (Le Reste, Nabbe, Manceau, et al. 2013), or analyses that cluster people according to condition patterns (Prados-Torres et al. 2014). However, similar analyses of people's wider circumstances were not identified, so an important extension of the work presented here would be to investigate such patterns using data reduction techniques such as latent class analysis (Collins & Lanza 2010) to identify patterns that go beyond the more biomedically-focussed disease clustering analyses in this field.[27] This would not only serve the purpose of challenging more essentialist conceptualisations. This kind of more comprehensive contextual information would also demonstrate the full extent of the challenges that some people with multiple conditions face. Such insights could then inform practice, such as the work being done to re-formulate guidelines and deliver more 'patient-centred' care (as noted in Chapter 2). As Wyatt et al. (2014) suggest, attempts to implement guidelines without appreciating the complex context of multiple conditions results in "*an absurd accumulation of work and complexity to which clinicians and patients can only respond with noncompliance*" (p.s99).

From a population health perspective, these kinds of analyses could help to shift the focus of interest away from single diseases, divorced from the reality of their individual and broader contexts, towards more holistic (and realistic) accounts of the ways in which poor health manifests in populations. A focus on single diseases brings with it a high risk that policy recommendations will be very biomedical (e.g. pharmacological management of hypertension) and individualistic in their orientation (e.g. adopting unhelpful 'behaviour' change approaches (Katikireddi et al. 2013)). In contrast, it is

[27] A fairly rudimentary attempt to do this was presented in Bromley (2014).

much harder to continue to offer simplistic solutions to scenarios that have been clearly presented as highly complex (though not impossible - the absence of actions to address the complexity of challenges set out in the Foresight (2008) obesity report springs to mind as an example of this).

The limitations associated with area-based measures of deprivation were noted above. One means of addressing this would be to include measures of individual-level socioeconomic position, such as occupation-based social class, income level or educational attainment (all of which are routinely collected in SHeS), in future analyses. However, in terms of identifying mechanisms that might account for the high levels of low wellbeing that accompany poor health and social disadvantage, different measures of phenomena that could lie on the causal pathway might be beneficial. However, Dunn's (2012) caution that "*the greatest challenge for social epidemiology is not to achieve more accurate measurement of variables*" (p.39) is important to heed here. The following recommendations for other measures that might potentially be of value have been framed in terms of items that could be added to SHeS. However, this is not intended to preclude the possibility of these also being explored using more intensive methods, such as qualitative interviews or ethnography. Indeed, for some it is likely that they would be more usefully explored solely by these means, without first having been included in a survey. Certainly, as Sayer argues, this combination of methods should be seen as a basic requirement in order to assess their potential status as mechanisms that produce outcomes:

> the discovery of empirical regularities may draw attention to objects whose causal powers might be responsible for the pattern and to conditions which are necessary for their existence and activation. But in order to confirm these, qualitative information is needed on the nature of objects involved and not merely more quantitative data on empirical associations. (Sayer 1992, cited in Dunn 2012, p.33).

Chapter 7 has already discussed the value that might be gained from having more information about the impact that conditions have on people's lives, in terms of their impairment of functional abilities and, linked to this, the extent to which people's aspirations for their lives are at odds with the realities of their existence. It would

certainly be advantageous to have better survey information about these aspects in order to create more distinctive measures of multiple condition experiences.

The high levels of mental distress experienced by younger people with multiple conditions in areas of high deprivation, coupled with the accounts of the complexity of the lives those patterns reflect (as shown in both studies by O'Brien et al. (2011; 2014)), suggest that there might be value in having survey measures of these kinds of complexities and thus open up the possibility of investigating their role in harming wellbeing. A large amount of time in the survey is devoted to establishing how many minutes of moderate or vigorous physical activity people expend each week, or how many units of alcohol or portions of fruit and vegetables they consume, due to their status as potential chronic disease risk factors (and the predominance of 'behavioural' measures in population surveys, allied to the arguable overemphasis of these kinds of accounts of health in UK policy circles (Katikireddi et al. 2013)). Although, as discussed in the presentation of some of these risks in Chapter 6, the fact that these were proximally-measured phenomena, their framing and interpretation need not be located solely at that level. However, measures of other kinds of stresses that immiserate people's lives and damage health are largely absent from SHeS. McCartney et al. (2013) provide a detailed examination of the potential impact of welfare reform on health inequality among working-age adults in Scotland, but note the lack of good measures to assess its impact. For example, while SHeS measures household income and receipt of social benefits, these measures do not capture the everyday work of living in poverty, or the kinds of assaults that this status brings, such as benefit sanctioning, food insecurity, precarious employment and financial insecurity. These absences are perhaps illustrative of the points made in Forbes & Wainwright's (2001) critique of official survey measures, noted in Chapter 4, though it is also worth highlighting that people's unwillingness to answer questions covering sensitive topics such as these is known to result in high levels of measurement error (Meyer et al. 2015).

Chapter 7 made the point that health-inputs rarely provide good explanations of health-outputs in the absence of social context. The additional measures of social

stressors suggested above would therefore help augment the survey's ability to capture these contextual aspects. However, it must not make the same mistake that medical sociology found itself accused of in the past, of making the body largely absent from these accounts (Kelly & Field 2004). The lives of people with multiple conditions are clearly encroached on by more than (just) the sum of their conditions, but aspects directly relating to their conditions are important too. Beyond the functional ability measures suggested above, other aspects of living with long-term poor health, such as pain, would also be valuable to measure, and would tap a more directly experienced (and often miserable) feature of health than measures of named conditions can do. The sociological literature on illness work described in Chapter 4 (Corbin & Strauss 1985; O'Brien et al. 2014) is highly relevant in the context of multiple conditions, one aspect of which is contact with health services, but the survey's measures of this are currently too crude to meaningfully differentiate the experiences of people whose lives feature multiple appointments. SHeS simply asks whether people had any in-patient and out-patient visits in the past year, using a simple binary indicator with no further granularity). But illness work is stressful beyond the sheer fact of these encounters. The connection between low wellbeing, multiple conditions and marital / partnership status would be worth exploring in the context of how people without partners manage their illness work, both practically, such as who accompanies them to medical appointments, as well as emotionally, in terms of help with the more stressful aspects of these encounters. The increasing stigmatisation of dependency explored by Peacock et al. (2014) is potentially instructive here in terms of identifying mechanisms that might produce low wellbeing among people with multiple conditions, especially at younger ages. This combination of circumstances involves multiple discordances relative to the experiences of the rest of their peer group and might therefore also feature multiple forms of stigma simultaneously.

The wellbeing patterns by age group presented in Chapter 6 suggest the possibility that another one of the many ways in which this group of people have very heterogeneous experiences will be related to the length of time they have spent living with multiple conditions. An extension of the approach to identifying sub-groups of people with multiple conditions based on their experiences, would be to investigate longitudinal

patterns in how people acquire their conditions. This could not be done with the existing dataset, but the UK has a number of established birth cohorts and other sources of longitudinal data that could be used to help distinguish between the experiences of people whose lives have featured multiple conditions for many years, and those with more recent experience of this status.

Conclusion

The literature review in Chapter 2 noted the various different definitional and conceptual boundaries that have provoked debates in this field, not least of which is the question of whether to define multiplicity as meaning two or more, or three or more, simultaneous conditions (e.g. Harrison (2014) argues that the lower of these thresholds is too expansive to be useful). In contrast, the overarching conclusion of this thesis is that while having two or more conditions can be a useful collective status of interest in its own right, changing the boundary at which people gain this collective status – or the boundaries between what does and doesn't count as an individual underlying condition - cannot *alone* address the highly heterogeneous nature of the health and wider social experiences that exist within this group. Higher boundary thresholds may well be more useful in certain contexts, but heterogeneity will always remain. In this way, the state of having multiple conditions could be viewed as a preliminary organising characteristic, from which others should then follow, thus enabling the duality of their similarity and diversity to be reflected and better understood.

The second key conclusion of this work is that it is valuable for all who seek to generate understandings of the lives of others to continually question the perspectives adopted and the tools used to do this. Following the format of the question posed by James (1963) at the start of this chapter, the corresponding questions that the approach taken in this thesis at least attempted to address were "what do they know of health, who only health know?" and, allied to this, "what do they know of data, who only data know?"

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Zola, I.K., 1972. Medicine as an institution of social control. *The Sociological Review*, 20, pp.487–504.

Appendix A: Literature review supplementary information

Systematic review MedLine search terms

1. multimorbid$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]
2. multi-morbid$.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]
3. 1 or 2
4. limit 3 to (english language and humans)
5. Comorbidity/
6. 4 or 5
7. systematic review.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]
8. 6 and 7
9. limit 8 to (english language and humans)
10. limit 9 to yr="2000 -Current"

Systematic Review Appraisal Checklist

The checklist was developed using criteria from two existing checklists:

- The Critical Appraisal Skills Programme (CASP) Systematic Review Checklist, dated 31.05.13, available from: www.casp-uk.net; and
- The Centre for Evidence Based Medicine Systematic Review Appraisal Checklist, dated 2005, available from: http://www.cebm.net/index.aspx?o=1157

- What question (PICO) did the systematic review address and was it clearly focused?
- Did the authors look for the right type of papers?
- Is the search strategy replicable?
- Is it likely that important, relevant studies were missed?
- Were the criteria used to select articles for inclusion appropriate?
- Is a PRISMA / PRISMA-style diagram presented?
- Did the review's authors do enough to assess the quality of the included studies?
- How are the results presented?
- What are the overall results of the review?
- Other points.

Appendix B: Centre for Population Health Sciences Ethical Review Checklist

University of Edinburgh,
Centre for Population Health Sciences
RESEARCH ETHICS SUBGROUP

Self-Audit Checklist for Level 1 Ethical Review for PGR projects

See **Intra** website for further information: http://www.cphs.mvm.ed.ac.uk/intra/research/ethicalReview.php

NOTE to student: *Completion of this form should be under the **oversight** of your supervisor. A good strategy would be to complete a draft as best you can, then discuss with your supervisor before completing a final copy for your supervisor to sign.*

***Proposed Project** (State research question and topic area, and briefly describe method/ data. Specify also countries in which data will be collected.):*

This PhD will investigate the prevalence of multimorbidity in the adult population in Scotland using secondary analysis of the Scottish Health Survey datasets from 1998 and 2008-2011. Additional anonymised data has been supplied by the Scottish Government and the Information Services Division of NHS Scotland, following applications to these organisations.

1. Bringing the University into disrepute

Is there any aspect of the proposed research which might bring the University into disrepute? YES/ NO

2. Data protection and consent

Are there any issues of DATA PROTECTION or CONSENT which are NOT adequately dealt with via established procedures? YES/ NO

These include well-established sets of undertakings. For example, a 'No' answer is justified *only if*:

(a) There is compliance with the University of Edinburgh's Data Protection procedures (see www.recordsmanagement.ed.ac.uk);

(b) Respondents give consent regarding the collection, storage and, if appropriate, archiving and destruction of data;

(c) Identifying information (eg consent forms) is held separately from data;

(d) There is Caldicott Guardian approval for (or approval will be obtained prior to) obtaining/ analysing NHS patient-data.

(e) There are no other special issues arising about confidentiality/consent.

3. Study participants

a) Will a study researcher be in direct contact with participants to collect data, whether face-to-face, or by telephone, electronic means or post, or by observation? (eg interviews, focus groups, questionnaires, assessments) YES/ NO

b) **Answer this only if qu. 3 above = 'YES':**
*In ethical terms, could any participants in the research be considered to be **'vulnerable'**?*
e.g. children & young people under age of 16, people who are in custody or care (incl. school), a marginalised/stigmatised group
Please tick one: 'vulnerable' ☐ not 'vulnerable' ☐

4. Moral issues and Researcher/Institutional Conflicts of Interest

Are there any SPECIAL MORAL ISSUES/CONFLICTS OF INTEREST? YES/ NO

(a) An example of conflict of interest for a researcher would be a financial or non-financial benefit for him/herself or for a relative of friend.

(b) Particular moral issues or concerns could arise, for example where the purposes of research are concealed, where respondents are unable to provide informed consent, or where research findings could impinge negatively/ differentially upon the interests of participants.

(c) Where there is a dual relationship between researcher and participant (eg where research is undertaken by practitioners so that the participant might be unclear as to the distinction between 'care' and research)

5. Protection of research subject confidentiality

Are there any issues of CONFIDENTIALITY which are NOT adequately handled by normal tenets of confidentiality for academic research? YES/ NO

These include well-established sets of undertakings that should be agreed with collaborating and participating individuals/organisations. For example, a 'No' answer is justified *only if*:

(a) There will be no attribution of individual responses;

(b) Individuals (and, where appropriate, organisations) are anonymised in stored data, publications and presentation;

(c) There has been specific agreement with respondents regarding feedback to collaborators and publication.

6. Potential physical or psychological harm, discomfort or stress

(a) Is there a FORSEEABLE POTENTIAL for PSYCHOLOGICAL HARM or STRESS for participants? YES/ NO

(b) Is there a FORSEEABLE POTENTIAL for PHYSICAL HARM or DISCOMFORT for participants? YES/ NO

(c) Is there a FORSEEABLE RISK to the researcher? YES/ NO

Examples of issues/ topics that have the potential to cause psychological harm, discomfort or distress and should lead you to answer 'yes' to this question include, but are not limited to:

relationship breakdown; bullying; bereavement; mental health difficulties; trauma / PTSD; violence or sexual violence; physical, sexual or emotional abuse in either children or adults.

7. Duty to disseminate research findings

Are there issues which will prevent all relevant stakeholders having access to a clear, understandable and accurate summary of the research findings if they wish?* YES/ NO

** If, and only if, you answered 'yes' to 3 above, 'stakeholders' includes the participants in the research*

Overall assessment

- If every answer above is a definite NO, the self-audit has been conducted and confirms the ***ABSENCE OF REASONABLY FORESEEABLE ETHICAL RISKS*** – *please tick box* ✓

  *This means that regarding this study, as currently self-audited, no further ethical review actions are required within CPHS. However, if in the coming weeks/months there is any change to the research plan envisaged now (and outlined above), the study should be **re-audited** against a Level 1 form, because it may be that the change made negates the absence of ethical risks signed off here.*

- If one or more answers are YES, then risks have been identified and prior to commencing any data collection **formal ethical review** is required - either:
  - by NHS REC (NB copy of ethics application and decision letter to be sent to CPHS Ethics); or
  - if not to be formally reviewed by NHS REC, then CPHS level 2/3 ethical review required. *[If either 4 is 'yes' or 3b is 'vulnerable' then it is possible level 3 review is required.]*

Two copies of this form should be taken for inclusion in the final dissertation/thesis and the original should be returned to the CPHS Ethics administrator.

Catherine Bromley	Prof. John Frank
Student Name	Supervisor Name
Student Signature	Supervisor Signature *

*** NOTE to supervisor:** *The CPHS Ethics Subgroup will not check this form (the light touch Level 1 form means we have insufficient detail to do so). By counter-signing this check-list as truly warranting all 'No' answers, you are taking responsibility, on behalf of CPHS and UoE, that the research proposed truly poses no potential ethical risks. Therefore, if there is any doubt on any issue, it would be a wise precaution to mark it as 'uncertain' and contact the Ethics Subgroup as to whether a level 2 form might be required as well. (See Intra Ethics website – URL at top of form)*

25 March 2014

Appendix C: Applications for data

Scottish Government Special Dataset Request

Your details

Please provide the following basic details about yourself.

✓ **Name**	Catherine Bromley
✓ **Job Title**	PhD Student
✓ **Organisation**	Centre for Population Health Sciences, University of Edinburgh
✓ **Address**	SCPHRP, 20 West Richmond Street, Edinburgh, EH8 9DX
✓ **e-mail**	catherine.bromley@ed.ac.uk
✓ **Telephone**	[redacted]

Research description

Provide a brief overview of your research, in particular your key aims and objectives.

✓ **Title**	Estimating the prevalence and impact of multimorbidity in adults using a general population survey
✓ **Purpose**	The project has three broad aims: 1. What is the prevalence of multimorbidity in adults in Scotland? 2. How does multimorbidity prevalence vary across population sub-groups? 3. What is the association between multimorbidity and key health outcomes? The first stage of the work will establish a definition (or definitions) of multimorbidity to be used in stages 2 and 3. The development of the definition needs to address the question of what counts as a condition. The data request in this application relates to this stage of the work.
✓ **Sponsor**	Economic and Social Research Council PhD Studentship

Methodology

Outline your research requirements, including how you plan on conducting your research and the timescales involved.

✓ **Methodology**	The survey currently records long-term conditions using ICD chapter codes. I would like to request access to the free-text ICD data to explore these issues: 1) Does the free-text information entered by interviewers offer any qualitative insights into how people describe their health conditions? 2) Can the information collected be used to apply more finely grained coding (below chapter-level), to help identify whether any multimorbidities are currently lost in the coding process? 3) Could alternative coding could be applied, such as the International Classification of Primary Care? In addition to asking about long-term conditions, the survey also asks about "other health problems". The data for this does not currently appear in all years' datasets. Preliminary analysis of the 1998 and 2008 data shows that people with long-term conditions who also report other health problems have significantly worse self-reported health, lower wellbeing and higher psychological distress than people with long-term conditions but no further health problems. I would therefore like to access the free-text answers given to this question, and to have the summary data added to all years, to see what kinds of health issues people are reporting. It is possible that this could reveal new insights about the health of people with long-term conditions that goes beyond simple measures of multimorbidity that rely on disease counts.
✓ **Timescale**	I would like to start this work in early January 2014, and hope to complete it by end of March 2014.
✓ **Contractors**	n/a

Data requirements

Please identify which variables you require, and what datasets these should be derived from.

Further information on the variables available within the SHeS are contained on the Data Archive website.

✓ **Variables**	1) Special dataset 2008 adult data (16+) only: illsM1-6 (free text – not currently in dataset) illcode1-6 (existing var) Longill (existing var) Limitac1 (existing var) HNotWhat (free text – not currently in dataset) HNCode1-3 (not currently in dataset) HNotAsk (existing var) HNote (existing var) Sex (existing var) Ag16g10 (existing var - if this is too disclosive, a flag identifying if 16-64 or 65+ - my main analysis will likely focus on 16-64 group). A dummy ID (that can be linked back to the dataset later if I want to add new codes as a result of this work). 2) Request to add some missing vars (non-disclosive) 2008/2009/2010/2011 combined file adult data (16+) only: HNCode1-3 (not currently in dataset for any years) HNote (already in 2008 dataset, missing in 09/10/11) HNotAsk (already in 2008 & 2010 datasets, missing in 09 & 11) 2003 – if these could be added to 2003 as well that would be great, but this is not a priority.
✓ **Data**	This request relates to the 2003, 2008, 2009, 2010, & 2011 datasets. I have chosen 2008 for the detailed analysis of free-text, but any year from the 2008-11 period would be fine, if that helps.

Please note, we may recommend that some of your variables are not provided, or are modified in some way, to protect the data confidentiality of our respondents.

Justification and Outcomes

Please provide justification for the use of a SHeS special dataset (as opposed to other alternatives), and how you propose using the resultant analysis.

✓ **Use of SHeS**	The Scottish Health Survey is the only source of general population, self-reported long-term condition data in Scotland that can be used to generate ICD coding. In addition, the question about additional health problems has never been analysed to date.
✓ **Outcomes**	The primary use of the data will be for my PhD analysis, contributing to the development of a measure of multimorbidity that can be used to explore differences within the population, and its impact on other health outcomes. The ICD and other health problem analysis will form the basis of at least one chapter of the final thesis, and I would also hope to present the wider results at conferences and in journal articles. I also hope that the process of looking in depth at the data collected about long-term conditions and other health problems will yield useful methodological insights about measuring health, in addition to substantive results about the profile of this group. This might also lead to recommendations about how the data are used that could benefit SHeS, and other population health surveys.

Signed declaration

I have read, understood and agreed to the terms and conditions as set out in the SHeS Special Dataset Request Pro-forma and Guidelines (April 2013) document.

✓ **Name**	Catherine Bromley
✓ **Date**	7 November 2013
✓ **Signature**	

Confidential Data Release Form

for users of NHS personal data

NHS National Services Scotland

1 User Details

Name: Catherine Bromley
Job title: PhD Student
Organisation: University of Edinburgh
Address: Scottish Collaboration for Public Health Research & Policy (SCPHRP)
University of Edinburgh
20 West Richmond Street
EH8 9DX
Tel No: [redacted]
Data Protection Reg No:

2 Sponsor Details

See Rule 6 for appropriate sponsor
Name: Professor John Frank
Job title: Director, SCPHRP
Organisation: University of Edinburgh
Address: Scottish Collaboration for Public Health Research & Policy (SCPHRP)
University of Edinburgh
20 West Richmond Street
EH8 9DX
Tel No: 0131 651 1593

3 Name(s) of all co-user(s):

Only the user and people listed here will have access to the data. This should include only those for whom access is essential to the work. Please see rule 3

N/A

4 Nature of data requested, including a list of variables required:

Only data essential to the proposed work should be requested.

SHeS minimum dataset – Survey year - 1998

5 All purposes for which data will be used, including publications:

No data which carries the risk of identification of an individual will be put into the public domain. Please refer to the Information Services Division's (ISD) Statistical Disclosure Control Protocol and/or discuss with the ISD Head of Statistics where disclosure is a concern. Please see Rule 5

The data will be used for analysis as part of a PhD project investigating multimorbidity in the Scottish population. The long-term mortality and morbidity implications of different multimorbidity definitions will be assessed using the linked data from 1998. The main thesis is due for submission in 2015, at least one journal publication based on this particular aspect of the work is anticipated, while others, based on analyses of multimorbidity from later rounds of the survey, are also expected.

6 Proposed method of transfer of data:
The final decision will be taken in consultation with the NSS analyst and should comply with NSS policy

Data will be transferred using the ISD online secure file system.

7 Measures in place to protect and use the data securely and confidentially:
Describe the physical and electronic systems for data storage and access

All data will be stored on University of Edinburgh remote network drives, where only the users have access to the data. Once the project has been completed, including successful award of the PhD and publication of all academic outputs, data will be destroyed as instructed.

8 Intended duration of use of data:
All users and co-users must agree to destroy the data after an agreed date using a certificated electronic destruction process. Paper data must also be destroyed

The thesis is due for submission in Autumn 2015. The academic article that follows should be published by December 2016 (although this date may change). After this date, all data will be destroyed upon request.

9 Date data to be destroyed:
Staff from NSS may contact to confirm destruction

December 2016.

User's Declaration
I declare that I understand and undertake to abide by the Rules for confidentiality, security and release of data received from NSS as specified in paragraphs 1-5 listed below.

Signature: Chris Bl Date: 13/8/14

Sponsor's Declaration
I declare that CATHERINE BROMLEY (name above as the user of the data requested), is a bona fide worker engaged in a reputable project and that the data requested can be entrusted to him/her in the knowledge that (s)he will conscientiously discharge his/her obligations in regard to confidentiality of the data, as stated in paragraphs 1-5 listed below. I am happy for him/her to receive these data.

Signature: Date: May 13, 2014

Professional registration no.: eg GMC/GDC

For NSS only
Caldicott Guardian, NHS National Services Scotland, Gyle Square, 1 South Gyle Crescent, Edinburgh, EH12 9EE

Information request number

Release authorised by

Date Senior manager (HOG or HOP)

Date Caldicott Guardian or deputy

Appendix D: Long-term conditions coding instructions and codeframe

Coding instructions

IllsM

Details are obtained of up to six types of long-standing illness. The text answers are recorded in the variables **IlsM1-IllsM6**. This should be coded, using the long-standing illness codeframes in **Appendix 2 and 3**, into the variables **IllCode 1-6** (appearing immediately after each instance of **IllsTxt**).

If there are two separate illnesses listed under the same **IlsM** variable, then these should be split as follows. Code first mentioned illness in the **IllCode** code linked to the **IlsM** code, remove the text of the second illness and put it into the first blank **IlsM** variable, and code the appropriate **IllCode** variable accordingly. In addition change the **More** variable (before the **IlsM** that the second illness has been moved to) from No to Yes.

Rules for coding long-standing illness

Code 41 Unclassifiable (no other codable complaint)

Exclusive code - this should only be used when the whole response is too vague to be coded into one of codes 01-40. This includes unspecific conditions like old age, war wounds etc (see codeframe for examples). This code can **only** be used in the 'first mention' columns. The editing program issues a warning if code 41 is used in any of the other columns.

Code 42 Complaint no longer present

Exclusive code - again it should be used only when the response given is **only** about a condition (or conditions) that no longer affects the respondent. This code can **only** be used in the 'first mention' columns. The editing program issues a warning if code 42 is used in any of the other columns.

Codes 01-40 can be used more than once if two different conditions are mentioned which both fall into the same category.

An exception to this is 'arthritis and rheumatism'. This is **not** two conditions, and so should **not** be given two separate codes; instead, code only one occurrence of code 34. (If two *specific* conditions were mentioned - eg osteoarthritis and rheumatoid arthritis - this *should* be coded as two occurrences.)

If more than 6 illnesses have been typed in by the interviewer, the first 6 mentioned should be coded.

Ilnesses which cannot be coded using the Longstanding Illness Codeframe or the ICD need to be sent to Andy MacGregor, ScotCen for coding using the Coding Queries Response Form.

01 Cancer (neoplasm) including lumps, masses, tumours and growths and benign (non-malignant) lumps and cysts
Acoustic neuroma
After effect of cancer (nes)
All tumours, growths, masses, lumps and cysts whether malignant or benign eg. tumour on brain, growth in bowel, growth on spinal cord, lump in breast
Cancers sited in any part of the body or system eg. Lung, breast, stomach
Colostomy caused by cancer
Cyst on eye, cyst in kidney.
General arthroma
Hereditary cancer
Hodgkin's disease
Hysterectomy for cancer of womb
Inch. leukaemia (cancer of the blood)
Lymphoma
Mastectomy (nes)
Neurofibromatosis
Part of intestines removed (cancer)
Pituitary gland removed (cancer)
Rodent ulcers
Sarcomas, carcinomas
Skin cancer, bone cancer
Wilms tumour

Endocrine/nutritional/metabolic diseases

02 Diabetes
Incl. Hyperglycaemia

03 Other endocrine/metabolic
Addison's disease
Beckwith - Wiedemann syndrome
Coeliac disease
Cushing's syndrome
Cystic fibrosis
Gilbert's syndrome
Hormone deficiency, deficiency of growth hormone, dwarfism
Hypercalcemia
Hypopotassaemia, lack of potassium
Malacia
Myxoedema (nes)
Obesity/overweight
Phenylketonuria
Rickets
Too much cholesterol in blood
Underactive/overactive thyroid, goitre
Water/fluid retention
Wilson's disease

Thyroid trouble and tiredness - code 03 only
Overactive thyroid and swelling in neck - code 03 only.

Mental, behavioural and personality disorders

04 Mental illness/anxiety/depression/nerves (nes)
Alcoholism, recovered not cured alcoholic
Angelman Syndrome
Anorexia nervosa
Anxiety, panic attacks
Asperger Syndrome
Autism/Autistic
Bipolar Affective Disorder
Catalepsy
Concussion syndrome
Depression
Drug addict
Dyslexia
Hyperactive child.
Nerves (nes)
Nervous breakdown, neurasthenia, nervous trouble
Phobias
Schizophrenia, manic depressive
Senile dementia, forgetfulness, gets confused
Speech impediment, stammer
Stress

Alzheimer's disease, degenerative brain disease = code 08

05 Mental handicap
Incl. Down's syndrome, Mongol
Mentally retarded, subnormal

Nervous system (central and peripheral including brain) - Not mental illness

06 Epilepsy/fits/convulsions
Grand mal
Petit mal
Jacksonian fit
Lennox-Gastaut syndrome
blackouts
febrile convulsions
fit (nes)

07 Migraine/headaches

08 Other problems of nervous system

Abscess on brain
Alzheimer's disease
Bell's palsy
Brain damage resulting from infection (eg. meningitis, encephalitis) or injury
Carpal tunnel syndrome
Cerebral palsy (spastic)
Degenerative brain disease
Fibromyalgia
Friedreich's Ataxia
Guillain-Barre syndrome
Huntington's chorea
Hydrocephalus, microcephaly, fluid on brain
Injury to spine resulting in paralysis
Metachromatic leucodystrophy
Motor neurone disease
Multiple Sclerosis (MS), disseminated sclerosis
Muscular dystrophy
Myalgic encephalomyelitis (ME)
Myasthenia gravis
Myotonic dystrophy
Neuralgia, neuritis
Numbness/loss of feeling in fingers, hand, leg etc
Paraplegia (paralysis of lower limbs)
Parkinson's disease (paralysis agitans)
Partially paralysed (nes)
Physically handicapped - spasticity of all limbs
Pins and needles in arm
Post viral syndrome (ME)
Removal of nerve in arm
Restless legs
Sciatica
Shingles
Spina bifida
Syringomyelia
Trapped nerve
Trigeminal neuralgia
Teraplegia

Eye complaints

09 Cataract/poor eye sight/blindness

Incl. operation for cataracts, now need glasses
Bad eyesight, restricted vision, partially sighted
Bad eyesight/nearly blind because of cataracts
Blind in one eye, loss of one eye
Blindness caused by diabetes
Blurred vision
Detached/scarred retina
Hardening of lens
Lens implants in both eyes
Short sighted, long sighted, myopia
Trouble with eyes (nes), eyes not good (nes)
Tunnel vision

10 Other eye complaints

Astigmatism
Buphthalmos
Colour blind
Double vision
Dry eye syndrome, trouble with tear ducts, watery eyes
Eye infection, conjunctivitis
Eyes are light sensitive
Floater in eye
Glaucoma
Haemorrhage behind eye
Injury to eye
Iritis
Keratoconus
Night blindness
Retinitis pigmentosa
Scarred cornea, corneal ulcers
Squint, lazy eye
Sty on eye

Ear complaints

11 Poor hearing/deafness

Conductive/nerve/noise induced deafness
Deaf mute/deaf and dumb
Heard of hearing, slightly deaf
Otosclerosis
Poor hearing after mastoid operation

12 Tinnitus/noises in the ear

Incl. pulsing in the ear

13 Meniere's disease/ear complaints causing balance problems
Labryrinthitis,
loss of balance - inner ear
Vertigo

14 Other ear complaints
Incl. otitis media - glue ear
Disorders of Eustachian tube
Perforated ear drum (nes)
Middle/inner ear problems
Mastoiditis
Ear trouble (nes),
Ear problem (wax)
Ear aches and discharges
Ear infection

Complaints of heart, blood vessels and circulatory system

15 Stroke/cerebral haemorrhage/cerebral thrombosis
Incl. stroke victim - partially paralysed and speech difficulty
Hemiplegia, apoplexy, cerebral embolism,
Cerebro - vascular accident

16 Heart attack/angina
Incl. coronary thrombosis, myocardial infarction

17 Hypertension/high blood pressure/blood pressure (nes)

18 Other heart problems
Aortic/mitral valve stenosis,
Aortic/mitral valve regurgitation
Aorta replacement
Atrial Septal Defect (ASD)
Cardiac asthma
Cardiac diffusion
Cardiac problems, heart trouble (nes)
Dizziness, giddiness, balance problems (nes)
Hardening of arteries in heart
Heart disease, heart complaint
Heart failure
Heart murmur, palpitations
Hole in the heart
Ischaemic heart disease
Pacemaker
Pains in chest (nes)
Pericarditis
St Vitus dance
Tachycardia, sick sinus syndrome
Tired heart
Valvular heart disease
Weak heart because of rheumatic fever
Wolff - Parkinson - White syndrome

Balance problems due to ear complaint = code 13

19 Piles/haemorrhoids incl. Varicose Veins in anus.

20 Varicose veins/phlebitis in lower extremities
Incl. various ulcers, varicose eczema

21 Other blood vessels/embolic
Arteriosclerosis, hardening of arteries (nes)
Arterial thrombosis
Artificial arteries (nes)
Blocked arteries in leg
Blood clots (nes)
Hand Arm Vibration Syndrome (White Finger)
Hypersensitive to the cold
Intermittent claudication
Low blood pressure/hypertension
Poor circulation
Pulmonary embolism
Raynaud's disease
Swollen legs and feet
Telangiectasia (nes)
Thrombosis (nes)
Varicose veins in Oesophagus
Wright's syndrome

NB Haemorrhage behind eye = code 10

Complaints of respiratory system

22 Bronchitis/emphysema
Bronchiectasis
Chronic bronchitis

23 Asthma
Bronchial asthma, allergic asthma
Asthma - allergy to house dust/grass/cat fur

NB *Exclude cardiac asthma - code 18*

24 Hayfever
Allergic rhinitis

25 Other respiratory complaints
Abscess on larynx
Adenoid problems, nasal polyps
Allergy to dust/cat fur
Bad chest (nes), weak chest - wheezy
Breathlessness
Bronchial trouble, chest trouble (nes)
Catarrh
Chest infections, get a lot of colds
Churg-Strauss syndrome
Chronic Obstructive Pulmonary Disease (COPD)
Coughing fits
Croup
Damaged lung (nes), lost lower lobe of left lung
Fibrosis of lung
Furred up airways, collapsed lung
Lung complaint (nes), lung problems (nes)
Lung damage by viral pneumonia
Paralysis of vocal cords
Pigeon fancier's lung
Pneumoconiosis, byssinosis, asbestosis and other industrial, respiratory disease
Recurrent pleurisy
Rhinitis (nes)
Sinus trouble, sinusitis
Sore throat, pharyngitis
Throat infection
Throat trouble (nes), throat irritation
Tonsillitis
Ulcer on lung, fluid on lung

TB (pulmonary tuberculosis) - code 37
Cystic fibrosis - code 03
Skin allergy - code 39
Food allergy - code 27
Allergy (nes) - code 41
Pilonidal sinus - code 39
Sick sinus syndrome - code 18
Whooping cough - code 37

If complaint is breathlessness with the cause also stated, code the cause:
breathlessness as a result of anaemia (code 38)
breathlessness due to hole in heart (code 18)
breathlessness due to angina (code 16)

Complaints of the digestive system

26 Stomach ulcer/ulcer (nes)/abdominal hernia/rupture
Double/inguinal/diaphragm/hiatus/umbilical hernia
Gastric/duodenal/peptic ulcer
Hernia (nes), rupture (nes)
Ulcer (nes)

27 Other digestive complaints (stomach, liver, pancreas, bile ducts, small intestine - duodenum, jejunum and ileum)
Cirrhosis of the liver, liver problems
Food allergies
Ileostomy
Indigestion, heart burn, dyspepsia
Inflamed duodenum
Liver disease, biliary artesia
Nervous stomach, acid stomach
Pancreas problems
Stomach trouble (nes), abdominal trouble (nes)
Stone in gallbladder, gallbladder problems
Throat trouble - difficulty in swallowing
Weakness in intestines

28 Complaints of bowel/colon (large intestine, caecum, bowel, colon, rectum)
Colitis, colon trouble, ulcerative colitis
Coleliac
Colostomy (nes)
Crohn's disease
Diverticulitis
Enteritis
Faecal incontinence/encopresis.
Frequent diarrhoea, constipation
Grumbling appendix
Hirschsprung's disease
Irritable bowel, inflammation of bowel
Polyp on bowel
Spastic colon

Exclude piles - code 19
Cancer of stomach/bowel - code 01

29 Complaints of teeth/mouth/tongue
Cleft palate, hare lip
Impacted wisdom tooth, gingivitis
No sense of taste
Ulcers on tongue, mouth ulcers

Complaints of genito-urinary system

30 Kidney complaints
Chronic renal failure
Horseshoe kidney, cystic kidney
Kidney trouble, tube damage, stone in the kidney
Nephritis, pyelonephritis
Nephrotic syndrome
Only one kidney, double kidney on right side
Renal TB
Uraemia

31 Urinary tract infection
Cystitis, urine infection

32 Other bladder problems/incontinence
Bed wetting, enuresis
Bladder restriction
Water trouble (nes)
Weak bladder, bladder complaint (nes)

Prostate trouble - code 33

33 Reproductive system disorders
Abscess on breast, mastitis, cracked nipple
Amenorrhea
Damaged testicles
Endometriosis
Gynaecological problems
Hysterectomy (nes)
Impotence, infertility
Menopause
Pelvic inflammatory disease/PID (female)
Period problems, flooding, pre-menstrual tension/syndrome
Prolapse (nes) if female
Prolapsed womb
Prostrate gland trouble
Turner's syndrome
Vaginitis, vulvitis, dysmenorrhoea

Musculo-skeletal - complaints of bones/joints/muscles

34 Arthritis/rheumatism/fibrositis
Arthritis as result of broken limb
Arthritis/rheumatism in any part of the body
Gout (*previously code 03*)
Osteoarthritis, rheumatoid arthritis, polymyalgia rheumatica
Polyarteritis Nodosa (*previously code 21*)
Psoriasis arthritis (also code psoriasis)
Rheumatic symptoms
Still's disease

35 Back problems/slipped disc/spine/neck
Back trouble, lower back problems, back ache
Curvature of spine
Damage, fracture or injury to back/spine/neck
Disc trouble
Lumbago, inflammation of spinal joint
Prolapsed invertebral discs
Schuermann's disease
Spondylitis, spondylosis
Worn discs in spine - affects legs

Exclude if damage/injury to spine results in paralysis - code 08
Sciatica or trapped nerve in spine - code 08

36 Other problems of bones/joints/muscles

Absence or loss of limb eg. lost leg in war, finger amputated, born without arms
Aching arm, stiff arm, sore arm muscle
Bad shoulder, bad leg, collapsed knee cap, knee cap removed
Brittle bones, osteoporosis
Bursitis, housemaid's knee, tennis elbow
Cartilage problems
Chondrodystrophia
Chondromalacia
Cramp in hand
Deformity of limbs eg. club foot, claw-hand, malformed jaw
Delayed healing of bones or badly set fractures
Deviated septum
Dislocations eg. dislocation of hip, clicky hip, dislocated knee/finger
Disseminated lupus
Dupuytren's contraction
Fibromyalgia
Flat feet, bunions,
Fracture, damage or injury to extremities, ribs, collarbone, pelvis, skull, eg. knee injury, broken leg, gun shot wounds in leg/shoulder, can't hold arm out flat - broke it as a child, broken nose
Frozen shoulder
Hip infection, TB hip
Hip replacement (nes)
Legs won't go, difficulty in walking
Marfan Syndrome
Osteomyelitis
Paget's disease
Perthe's disease
Physically handicapped (nes)
Pierre Robin syndrome
Schlatter's disease
Sever's disease
Stiff joints, joint pains, contraction of sinews, muscle wastage
Strained leg muscles, pain in thigh muscles
Systemic sclerosis, myotonia (nes)
Tenosynovitis
Torn muscle in leg, torn ligaments, tendonitis
Walk with limp as a result of polio, polio (nes), after affects of polio (nes)
Weak legs, leg trouble, pain in legs

Muscular dystrophy - code 08

37 Infectious and parasitic disease

AIDS, AIDS carrier, HIV positive (*previously code 03*)
Athlete's foot, fungal infection of nail
Brucellosis
Glandular fever
Malaria
Pulmonary tuberculosis (TB)
Ringworm
Schistosomiasis
Tetanus
Thrush, candida
Toxoplasmosis (nes)
Tuberculosis of abdomen
Typhoid fever
Venereal diseases
Viral hepatitis
Whooping cough

After effect of Poliomyelitis, meningitis, encephalitis - code to site/system
Ear/throat infections etc - code to site

38 Disorders of blood and blood forming organs and immunity disorders

Anaemia, pernicious anaemia
Blood condition (nes), blood deficiency
Haemophilia
Idiopathic Thrombochopenic Purpura (ITP)
Immunodeficiences
Polycthaemia (blood thickening), blood to thick
Purpura (nes)
Removal of spleen
Sarcoidosis (*previously code 37*)
Sickle cell anaemia/disease
Thalassaemia
Thrombocythenia

Leukaemia - code 01

39 Skin complaints

abscess in groin
acne
birth mark
burned arm (nes)
carbuncles, boils, warts, verruca
cellulitis (nes)
chilblains
corns, calluses
dermatitis
Eczema
epidermolysis, bulosa
impetigo

ingrown toenails
pilonidal sinusitis
Psoriasis, psoriasis arthritis (also code arthritis)
skin allergies, leaf rash, angio-oedema
skin rashes and irritations
skin ulcer, ulcer on limb (nes)

Rodent ulcer - code 01
Varicose ulcer, varicose eczema - code 20

40 Other complaints
adhesions
dumb, no speech
fainting
hair falling out, alopecia
insomnia
no sense of smell
nose bleeds
sleepwalking
travel sickness

Deaf and dumb - code 11 only

41 Unclassifiable (no other codable complaint)
after affects of meningitis (nes)
allergy (nes), allergic reaction to some drugs (nes)
electrical treatment on cheek (nes)
embarrassing itch (nes)
Forester's disease (nes)
general infirmity
generally run down (nes)
glass in head - too near temple to be removed (nes)
had meningitis - left me susceptible to other things (nes)
internal bleeding (nes)
ipinotaligia
old age/weak with old age
swollen glands (nes)
tiredness (nes)
war wound (nes), road accident injury (nes)
weight loss (nes)

42 Complaint no longer present

Only use this code if it is actually stated that the complaint no longer affects the informant.

Exclude if complaint kept under control by medication - code to site/system.

99 Not Answered/Refusal

Appendix E: Questionnaire material

The Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS)

Please read this carefully:

Below are some statements about feelings and thoughts.

Please tick the box that best describes your experience of each over the last 2 weeks

	None of the time	Rarely	Some of the time	Often	All of the time
I've been feeling optimistic about the future					
I've been feeling useful					
I've been feeling relaxed					
I've been feeling interested in other people					
I've had energy to spare					
I've been dealing with problems well					
I've been thinking clearly					
I've been feeling good about myself					
I've been feeling close to other people					
I've been feeling confident					
I've been able to make up my own mind about things					
I've been feeling loved					
I've been interested in new things					
I've been feeling cheerful					

The General Health Questionnaire 12 (GHQ12)

GENERAL HEALTH OVER THE LAST FEW WEEKS

Please read this carefully:

We should like to know how your health has been in general over **the past few weeks**. Please answer ALL the questions by ticking the box below the answer which you think most applies to you.

Been able to concentrate on whatever you're doing?	**Better than usual**	**Same as usual**	**Less than usual**	**Much less than usual**
Lost much sleep over worry?	**Not at all**	**No more than usual**	**Rather more than usual**	**Much more than usual**
Felt you were playing a useful part in things?	**More so than usual**	**Same as usual**	**Less useful than usual**	**Much less useful**
Felt capable of making decisions about things?	**More so than usual**	**Same as usual**	**Less capable than usual**	**Much less capable**
Felt constantly under strain?	**Not at all**	**No more than usual**	**Rather more than usual**	**Much more than usual**
Felt you couldn't overcome your difficulties?	**Not at all**	**No more than usual**	**Rather more than usual**	**Much more than usual**
Been able to enjoy your normal day-to-day activities?	**More so than usual**	**Same as usual**	**Less so than usual**	**Much less than usual**
Been able to face up to your problems?	**More so than usual**	**Same as usual**	**Less so than usual**	**Much less able**
Been feeling unhappy and depressed?	**Not at all**	**No more than usual**	**Rather more than usual**	**Much more than usual**
Been losing confidence in yourself?	**Not at all**	**No more than usual**	**Rather more than usual**	**Much more than usual**
Been thinking of yourself as a worthless person?	**Not at all**	**No more than usual**	**Rather more than usual**	**Much more than usual**
Been feeling reasonably happy, all things considered?	**More so than usual**	**About same as usual**	**Less so than usual**	**Much less than usual**

The Clinical Interview Schedule – revised (CIS-R)

The following questions were asked face-to-face by nurses using computer-assisted personal interviewing (CAPI). The following is a transcript of the CAPI programme, including the routing instructions.

Depression
ASK ALL WITH NURSE VISIT
[AnxInt]
I'm now going to ask you some questions about how you've been feeling lately and if you've been feeling depressed, worried or anxious.
NURSE: This is the start of the anxiety, depression and self-harm questions. Some people might be uncomfortable answering some of the questions or might find them difficult.
If the respondent is uncomfortable answering any question or appears distressed at any point you might need to give them some time to compose themselves before carrying on with the rest of the visit.
If you need to skip a question just press <Ctrl R>. If they don't wish to answer any further questions in this section press <Ctrl R> at each question until you get to the next set of questions.
Press <1> and <Enter> to continue.

[G1]
Almost everyone becomes sad, miserable or depressed at times.
Have you had a spell of feeling sad, miserable or depressed in the past month?
1 Yes
2 No

[G2]
During the past month, have you been able to enjoy or take an interest in things as much as you usually do?
1 Yes
2 No/no enjoyment or interest

IF G1 = Yes THEN
[G4]
NURSE: PLEASE USE INFORMANTS OWN WORDS IF POSSIBLE
In the past week have you had a spell of feeling sad, miserable or depressed?
1 Yes
2 No

IF G2 = No THEN
[G5]
NURSE: PLEASE USE INFORMANTS OWN WORDS IF POSSIBLE
In the past week have you been able to enjoy or take an interest in things as much as usual?
1 Yes
2 No/no enjoyment or interest

IF (G4 = Yes) OR IF (G5 = No/no enjoyment or interest) THEN
[G6]
Since last [Sunday / Monday / Tuesday / Wednesday / Thursday / Friday / Saturday] on how many days have you felt [depressed or unable to take an interest in things / sad, miserable or depressed / unable to enjoy or take an interest in things]?
1 4 days or more
2 1 to 3 days
3 None

IF (G4 = Yes) OR IF (G5 = No/no enjoyment or interest) THEN
[G7]
Have you felt [depressed or unable to take an interest in things / sad, miserable or depressed /unable to enjoy or take an interest in things] for more than 3 hours in total (on any day in the past week)?
1 Yes
2 No

IF (G4 = Yes) OR IF (G5 = No/no enjoyment) THEN
[G9]
In the past week when you felt sad, miserable or depressed/unable to enjoy or take an interest in things, did you ever become happier when something nice happened, or when you were in company?
1 Yes, at least once
2 No

IF (G4 = Yes) OR IF (G5 = No/no enjoyment) THEN
[G10]
SHOW CARD B
How long have you been feeling sad, miserable or depressed/unable to enjoy or take an interest in things as you have described?
1 less than 2 weeks
2 2 weeks but less than 6 months
3 6 months but less than 1 year
4 1 year but less than 2 years
5 2 years but less than 5 years
6 5 years but less than 10 years
7 10 years or more

Anxiety
ASK ALL WITH NURSE VISIT
[J1]
Have you been feeling anxious or nervous in the past month?
2 No

IF J1 = No THEN
[J2]
In the past month, did you ever find your muscles felt tense or that you couldn't relax?
1 Yes
2 No

ASK ALL WITH NURSE VISIT
[J3]
Some people have phobias; they get nervous or uncomfortable about specific things or situations when there is no real danger. For instance they may get extremely anxious when in confined spaces, or they may have a fear of heights. Others become nervous at the sight of things like blood or spiders.
In the past month have you felt anxious, nervous or tense about any specific things when there was no real danger?
1 Yes
2 No

IF RESPONDENT HAS EXPERIENCED ANXIETY AND PHOBIA THEN
[J5]
In the past month, when you felt anxious/nervous/tense, was this always brought on by the phobia about some specific situation or thing or did you sometimes feel generally anxious/nervous/tense?
1 Always brought on by phobia
2 Sometimes generally anxious

IF RESPONDENT HAS EXPERIENCED ANXIETY AND PHOBIA AND IF J5 = Sometimes generally anxious THEN
[J6]
The next questions are concerned with general anxiety/nervousness/tension only.
I will ask you about the anxiety which is brought on by the phobia about specific things or situations later.
On how many of the past seven days have you felt generally anxious/nervous/tense?
1 4 days or more
2 1 to 3 days
3 None

IF RESPONDENT HAS EXPERIENCED GENERAL ANXIETY ONLY THEN
[J7]
On how many of the past seven days have you felt generally anxious/nervous/tense?
1 4 days or more
2 1 to 3 days
3 None

IF RESPONDENT HAS EXPERIENCED ANXIETY FOR AT LEAST 1 DAY (AT J6 OR J7) THEN
[J8]
In the past week, has your anxiety/nervousness/tension been:
RUNNING PROMPT
1 ...very unpleasant
2 ...a little unpleasant
3 ...or not unpleasant?

[J9]
SHOW CARD C
In the past week, when you've been anxious/nervous/tense, have you had any of the symptoms shown on this card?
1 Yes
2 No

IF RESPONDENT HAS EXPERIENCED ANY OF THE SYMPTOMS LISTED ON SHOWCARD C [J9A]*
SHOW CARD C
Which of these symptoms did you have when you felt anxious/nervous/tense?
CODE ALL THAT APPLY
1 Heart racing or pounding [J9A1]
2 Hands sweating or shaking [J9A2]
3 Feeling dizzy [J9A3]
4 Difficulty getting your breath [J9A4]
5 Butterflies in stomach [J9A5]
6 Dry mouth [J9A6]
7 Nausea or feeling as though you wanted to vomit [J9A7]

IF RESPONDENT HAS EXPERIENCED ANXIETY FOR AT LEAST 1 DAY (AT J6 OR J7) THEN [J10]
Have you felt anxious/nervous/tense for more than 3 hours in total on any one of the past seven days?
1 Yes
2 No

[J11]
How long have you had these feelings of general anxiety/nervousness/tension as you described?
SHOW CARD B AGAIN
1 less than 2 weeks
2 2 weeks but less than 6 months
3 6 months but less than 1 year
4 1 year but less than 2 years
5 2 years or more

Appendix F: SPSS syntax to create the multiple conditions measure

Stage 1: ungrouping the long-term condition chapters

Counting the conditions

```
mis vals longill08 illcode1 illcode2 illcode3 illcode4 illcode5 illcode6 ().

DO REPEAT xcomp=xcompm1 xcompm2 xcompm3 xcompm4 xcompm5 xcompm6
xcompm7 xcompm8 xcompm9 xcompm10 xcompm11 xcompm12 xcompm13 xcompm14
xcompm15 xcompm16 xcompm17 xcompm18 xcompm19 xcompm20 xcompm21
xcompm22 xcompm23 xcompm24 xcompm25 xcompm26 xcompm27 xcompm28
xcompm29 xcompm30 xcompm31 xcompm32 xcompm33 xcompm34 xcompm35
xcompm36 xcompm37 xcompm38 xcompm39 xcompm40 xcompm41 xcompm42 xcompm .

COMPUTE xcomp=0.
IF (longill08<0) xcomp=-9.
END REPEAT.

DO REPEAT xill=illcode1 illcode2 illcode3 illcode4 illcode5 illcode6.
IF (xill=1) xcompm1=1.
IF (xill=2) xcompm2=1.
IF (xill=3) xcompm3=1.
IF (xill=4) xcompm4=1.
IF (xill=5) xcompm5=1.
IF (xill=6) xcompm6=1.
IF (xill=7) xcompm7=1.
IF (xill=8) xcompm8=1.
IF (xill=9) xcompm9=1.
IF (xill=10) xcompm10=1.
IF (xill=11) xcompm11=1.
IF (xill=12) xcompm12=1.
IF (xill=13) xcompm13=1.
IF (xill=14) xcompm14=1.
IF (xill=15) xcompm15=1.
IF (xill=16) xcompm16=1.
IF (xill=17) xcompm17=1.
IF (xill=18) xcompm18=1.
IF (xill=19) xcompm19=1.
IF (xill=20) xcompm20=1.
IF (xill=21) xcompm21=1.
IF (xill=22) xcompm22=1.
IF (xill=23) xcompm23=1.
IF (xill=24) xcompm24=1.
IF (xill=25) xcompm25=1.
IF (xill=26) xcompm26=1.
IF (xill=27) xcompm27=1.
```

```
IF (xill=28) xcompm28=1.
IF (xill=29) xcompm29=1.
IF (xill=30) xcompm30=1.
IF (xill=31) xcompm31=1.
IF (xill=32) xcompm32=1.
IF (xill=33) xcompm33=1.
IF (xill=34) xcompm34=1.
IF (xill=35) xcompm35=1.
IF (xill=36) xcompm36=1.
IF (xill=37) xcompm37=1.
IF (xill=38) xcompm38=1.
IF (xill=39) xcompm39=1.
IF (xill=40) xcompm40=1.
IF (xill=41) xcompm41=1.
IF (xill=42) xcompm42=1.
END REPEAT.

IF (longill08 = 2) xcompm = 1.
COMPUTE xcompm99 = 0 .
IF (longill08 = 1 & ANY(illcode1,41,42,-1,-8,-9)) xcompm99 = 1 .
IF (longill08<0) xcompm99 = -9.
exe.
VARIABLE LABELS xcompm1 '(D) Neoplasms & benign growths'
 /xcompm2 '(D) Diabetes'
 /xcompm3 '(D) Other endocrine / met'
 /xcompm4 '(D) Mental illness/anxiety etc'
 /xcompm5 '(D) Learning disability'
 /xcompm6 '(D) Epilepsy'
 /xcompm7 '(D) Migraine/headaches'
 /xcompm8 '(D) Other problems of Nervous System'
 /xcompm9 '(D) cataract/blindness'
 /xcompm10 '(D) Other Eye complaints'
 /xcompm11 '(D) Poor hearing/deafness'
 /xcompm12 '(D) Tinnutus etc'
 /xcompm13 "(D) Meniere's / balance problems"
 /xcompm14 '(D) Other Ear complaints'
 /xcompm15 '(D) Stroke / cerebral haem'
 /xcompm16 '(D) Heart attack / angina'
 /xcompm17 '(D) High blood pressure'
 /xcompm18 '(D) Other heart problems'
 /xcompm19 '(D) Piles / haemorrhoids'
 /xcompm20 '(D) Varicose veins'
 /xcompm21 '(D) Other blood vessels / embolic'
 /xcompm22 '(D) Bronchitis/emphysema'
 /xcompm23 '(D) Asthma'
 /xcompm24 '(D) Hay fever'
 /xcompm25 '(D) Other respiratory complaints (inc sinus)'
 /xcompm26 '(D) Stomach ulcer / abnominal hernia'
 /xcompm27 '(D) Other digestive complaints (stomach / liver / bile / pancreas / small int'
 /xcompm28 '(D) Complaints of bowel / large intestine'
```

```
 /xcompm29 '(D) Complaints of teeth/mouth/tongue'
 /xcompm30 '(D) Kidney complaints'
 /xcompm31 '(D) UTI'
 /xcompm32 '(D) Other bladder problems'
 /xcompm33 '(D) Reproductive system disorders'
 /xcompm34 '(D) Arthritis/rheumatism/fibrositis'
 /xcompm35 '(D) Back problems/slipped disc/spine/neck'
 /xcompm36 '(D) Other problems of bones/joints/muscles'
 /xcompm37 '(D) Infectious and parasitic disease'
 /xcompm38 '(D) Disorders of blood and blood forming organs and immunity disorders'
 /xcompm39 '(D) Skin complaints'
 /xcompm40 '(D) Other complaints'
 /xcompm41 '(D) Unclassifiable'
 /xcompm42 '(D) No longer present'
 /xcompm '(D) No long standing illness'
 /xcompm99 "(D) Unclass/NLP/inadeq describe" .

VALUE LABELS xcompm1 TO xcompm99
0 'no condition present'
1 'has condition'.

**New condition count.

IF (longill08 = 2) xcondcnt = 0 .
DO IF (longill08 = 1).
COUNT xcondcnt = xcompm1 TO xcompm40 (1) .
END IF .
IF (longill08 = 1 & (any(illcode1,41,42,97,99) | illcode1<0)) xcondcnt = 1 .
IF (longill08<0) xcondcnt = -9.
VARIABLE LABEL xcondcnt "(D) New: Number of UNgrouped condition categories" .
VALUE LABELS xcondcnt
0 'no LS illness'.
fre xcondcnt.

***The 3 cases coded 42 (no longer present) at illcode1 recoded to 0 LTC.
if illcode1=42 xcondcnt=0.

***And this should be applied to original var.

if illcode1=42 and longill08=1  condcnt=0.

**The case coded 99 at illcode1 and 13 at illcode2 is multimorbid, so correct the original
vars.
if cpserialA=2050603101 condcnt=2.
if cpserialA=2050603101 xcondcnt=2.
```

Summary measure of multiple conditions

```
recode condcnt xcondcnt (2 thru hi=2) (else=copy) into condcnt_2 xcondcnt_2.
```

```
recode condcnt xcondcnt (3 thru hi=3) (else=copy) into condcnt_3 xcondcnt_3.
exe.
Var label condcnt_2 "(D) Original condition count: 2+ conditions".
Var label xcondcnt_2 "(D) Ungrouped chapters condition count: 2+ conditions".
Var label condcnt_3 "(D) Original condition count: 3+ conditions".
Var label xcondcnt_3 "(D) Ungrouped chapters condition count: 3+ conditions".
```

Stage 1: including all coded long-term conditions

Counting the conditions

```
count Cancer= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (1).
count Diabetes= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (2).
count OthEndc= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (3).
count Psych= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (4).
count LearnD= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (5).
count Epileps= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (6).
count Migraine= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (7).
count OthNerv= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (8).
count BadEyes= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (9).
count OthEyes= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (10).
count Deaf= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (11).
count Tinnit= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (12).
count Meniere= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (13).
count OthEars= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (14).
count Stroke= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (15).
count MI= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (16).
count HBP= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (17).
count OthHrt= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (18).
count Piles= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (19).
count Varic= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (20).
count OthBlod= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (21).
count Bronch= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (22).
count Asthma= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (23).
count Hayf= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (24).
count OthResp= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (25).
count Ulcer= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (26).
count OthDig= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (27).
count Bowel= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (28).
count Mouth= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (29).
count Kidney= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (30).
count UTI= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (31).
count OthBlad= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (32).
count Reprod= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (33).
count Arthritis= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (34).
count BackP= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (35).
count OthMusc= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (36).
count infect = IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (37).
```

```
count Blood= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (38).
count skin= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (39).
count Other= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (40).
count unclass= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (41).
count Cured= IllCode1 IllCode2 IllCode3 IllCode4 IllCode5 IllCode6 (42).
Exe.

***Make binaries of these vars.
Recode Cancer Diabetes OthEndc Psych LearnD Epileps Migraine OthNerv BadEyes OthEyes
Deaf Tinnit Meniere OthEars Stroke MI HBP OthHrt Piles Varic OthBlod Bronch Asthma Hayf
OthResp Ulcer OthDig Bowel Mouth Kidney UTI OthBlad Reprod Arthritis BackP OthMusc
infect Blood skin Other unclass Cured (1 thru hi=1) (else=copy) into Cancer2 Diabetes2
OthEndc2 Psych2 LearnD2 Epileps2 Migraine2 OthNerv2 BadEyes2 OthEyes2 Deaf2 Tinnit2
Meniere2 OthEars2 Stroke2 MI2 HBP2 OthHrt2 Piles2 Varic2 OthBlod2 Bronch2 Asthma2
Hayf2 OthResp2 Ulcer2 OthDig2 Bowel2 Mouth2 Kidney2 UTI2 OthBlad2 Reprod2 Arthritis2
BackP2 OthMusc2 infect2 Blood2 skin2 Other2 unclass2 Cured2.
exe.

If longill08 LT 0 cancer = -1 .
if longill08 LT 0 Diabetes = -1 .
if longill08 LT 0 OthEndc = -1 .
if longill08 LT 0 Psych = -1 .
if longill08 LT 0 LearnD = -1 .
if longill08 LT 0 Epileps = -1 .
if longill08 LT 0 Migraine = -1 .
if longill08 LT 0 OthNerv = -1 .
if longill08 LT 0 BadEyes = -1 .
if longill08 LT 0 OthEyes = -1 .
if longill08 LT 0 Deaf = -1 .
if longill08 LT 0 Tinnit = -1 .
if longill08 LT 0 Meniere = -1 .
if longill08 LT 0 OthEars = -1 .
if longill08 LT 0 Stroke = -1 .
if longill08 LT 0 MI = -1 .
if longill08 LT 0 HBP = -1 .
if longill08 LT 0 OthHrt = -1 .
if longill08 LT 0 Piles = -1 .
if longill08 LT 0 Varic = -1 .
if longill08 LT 0 OthBlod = -1 .
if longill08 LT 0 Bronch = -1 .
if longill08 LT 0 Asthma = -1 .
if longill08 LT 0 Hayf = -1 .
if longill08 LT 0 OthResp = -1 .
if longill08 LT 0 Ulcer = -1 .
if longill08 LT 0 OthDig = -1 .
if longill08 LT 0 Bowel = -1 .
if longill08 LT 0 Mouth = -1 .
if longill08 LT 0 Kidney = -1 .
if longill08 LT 0 UTI = -1 .
if longill08 LT 0 OthBlad = -1 .
```

```
if longill08 LT 0 Reprod = -1 .
if longill08 LT 0 Arthritis = -1 .
if longill08 LT 0 BackP = -1 .
if longill08 LT 0 OthMusc = -1 .
if longill08 LT 0 infect = -1 .
if longill08 LT 0 Blood = -1 .
if longill08 LT 0 skin = -1 .
if longill08 LT 0 Other = -1 .
if longill08 LT 0 unclass = -1 .
if longill08 LT 0 Cured = -1 .
if longill08 LT 0 Cancer2 = -1 .
if longill08 LT 0 Diabetes2 = -1 .
if longill08 LT 0 OthEndc2 = -1 .
if longill08 LT 0 Psych2 = -1 .
if longill08 LT 0 LearnD2 = -1 .
if longill08 LT 0 Epileps2 = -1 .
if longill08 LT 0 Migraine2 = -1 .
if longill08 LT 0 OthNerv2 = -1 .
if longill08 LT 0 BadEyes2 = -1 .
if longill08 LT 0 OthEyes2 = -1 .
if longill08 LT 0 Deaf2 = -1 .
if longill08 LT 0 Tinnit2 = -1 .
if longill08 LT 0 Meniere2 = -1 .
if longill08 LT 0 OthEars2 = -1 .
if longill08 LT 0 Stroke2 = -1 .
if longill08 LT 0 MI2 = -1 .
if longill08 LT 0 HBP2 = -1 .
if longill08 LT 0 OthHrt2 = -1 .
if longill08 LT 0 Piles2 = -1 .
if longill08 LT 0 Varic2 = -1 .
if longill08 LT 0 OthBlod2 = -1 .
if longill08 LT 0 Bronch2 = -1 .
if longill08 LT 0 Asthma2 = -1 .
if longill08 LT 0 Hayf2 = -1 .
if longill08 LT 0 OthResp2 = -1 .
if longill08 LT 0 Ulcer2 = -1 .
if longill08 LT 0 OthDig2 = -1 .
if longill08 LT 0 Bowel2 = -1 .
if longill08 LT 0 Mouth2 = -1 .
if longill08 LT 0 Kidney2 = -1 .
if longill08 LT 0 UTI2 = -1 .
if longill08 LT 0 OthBlad2 = -1 .
if longill08 LT 0 Reprod2 = -1 .
if longill08 LT 0 Arthritis2 = -1 .
if longill08 LT 0 BackP2 = -1 .
if longill08 LT 0 OthMusc2 = -1 .
if longill08 LT 0 infect2 = -1 .
if longill08 LT 0 Blood2 = -1 .
if longill08 LT 0 skin2 = -1 .
if longill08 LT 0 Other2 = -1 .
```

```
if longill08 LT 0 unclass2 = -1 .
if longill08 LT 0 Cured2 = -1 .
exe.
val labs cancer2 TO cured2 1 "Has condition" 0 "Does not" -1 "Missing".
fre cancer2 TO cured2.
fre cancer to cured.

miss vals cancer2 TO cured2 (lo thru -1).
miss vals cancer TO cured (lo thru -1).


***FROM HERE ON THE SYNTAX IS COUNTING MULTIPLE CODES WITHIN CONDITIONS.

count conds1=  Cancer Diabetes OthEndc Psych LearnD Epileps Migraine OthNerv BadEyes
OthEyes Deaf Tinnit Meniere OthEars Stroke MI HBP OthHrt Piles Varic OthBlod Bronch
Asthma Hayf OthResp Ulcer OthDig Bowel Mouth Kidney UTI OthBlad Reprod Arthritis
BackP OthMusc infect Blood skin Other unclass (1).
fre conds1.

count conds2=  Cancer Diabetes OthEndc Psych LearnD Epileps Migraine OthNerv BadEyes
OthEyes Deaf Tinnit Meniere OthEars Stroke MI HBP OthHrt Piles Varic OthBlod Bronch
Asthma Hayf OthResp Ulcer OthDig Bowel Mouth Kidney UTI OthBlad Reprod Arthritis
BackP OthMusc infect Blood skin Other unclass (2).
fre conds2.

count conds3=  Cancer Diabetes OthEndc Psych LearnD Epileps Migraine OthNerv BadEyes
OthEyes Deaf Tinnit Meniere OthEars Stroke MI HBP OthHrt Piles Varic OthBlod Bronch
Asthma Hayf OthResp Ulcer OthDig Bowel Mouth Kidney UTI OthBlad Reprod Arthritis
BackP OthMusc infect Blood skin Other unclass (3).
fre conds3.

count conds4=  Cancer Diabetes OthEndc Psych LearnD Epileps Migraine OthNerv BadEyes
OthEyes Deaf Tinnit Meniere OthEars Stroke MI HBP OthHrt Piles Varic OthBlod Bronch
Asthma Hayf OthResp Ulcer OthDig Bowel Mouth Kidney UTI OthBlad Reprod Arthritis
BackP OthMusc infect Blood skin Other unclass (4).
fre conds4.

count conds5=  Cancer Diabetes OthEndc Psych LearnD Epileps Migraine OthNerv BadEyes
OthEyes Deaf Tinnit Meniere
   OthEars Stroke MI HBP OthHrt Piles Varic OthBlod Bronch Asthma Hayf OthResp Ulcer
OthDig Bowel
   Mouth Kidney UTI OthBlad Reprod Arthritis BackP OthMusc infect Blood skin Other
unclass (5).
fre conds5.

count conds6=  Cancer Diabetes OthEndc Psych LearnD Epileps Migraine OthNerv BadEyes
OthEyes Deaf Tinnit Meniere OthEars Stroke MI HBP OthHrt Piles Varic OthBlod Bronch
Asthma Hayf OthResp Ulcer OthDig Bowel Mouth Kidney UTI OthBlad Reprod Arthritis
BackP OthMusc infect Blood skin Other unclass (6).
fre conds6.
```

```
***CONDITION COUNT VARIABLE.

miss vals longill08 illcode1 ().
compute conds1x=-99.
if longill08=2 conds1x=0.
if conds1=0 conds1x=0.
if conds1 gt 0 conds1x=conds1.
if conds2=1 conds1x=conds1+2.
if conds2=2 conds1x=conds1+4.
if conds3=1 conds1x=conds1+3.
if conds4=1 conds1x=conds1+4.
if conds6=1 conds1x=conds1+6.
if illcode1=99 and longill08=1  conds1x=1.
if illcode1=42 and longill08=1  conds1x=0.
if illcode1=-1 and longill08=1  conds1x=1.
if longill08 LT 0 conds1x=longill08.
exe.
Var lab conds1x "(D) UNgrouped condition categories and all conditions counted".
fre conds1x.

*Here is the check that identifies the person with a code 99 at illcode1 and code 13 at
illcode2, do not adjust the underlying binary vars.

temp.
sel if illcode1=99.
list cpserialA illcode1 illcode2 illcode3 conds1x.

*Can only be corrected by serial number as the code 99 conditions were not included in the
condition count binaries.

if cpserialA=2050603101 conds1x=2.

fre conds1x.

*Correct it for condcnt.
fre condcnt xcondcnt.
if cpserialA=2050603101 condcnt=2.
if cpserialA=2050603101 xcondcnt=2.

*Recode the people with resolved conditions.
if illcode1=42 and longill08=1  condcnt=0.
if illcode1=42 and longill08=1  xcondcnt=0.
```

Summary measure of multiple conditions

```
recode conds1x (2 thru hi=2) (else=copy) into conds1x_2.
recode conds1x (3 thru hi=3) (else=copy) into conds1x_3.
exe.
```

```
Var label conds1x_2 "(D) Ungrouped chapters and all conds counted: 2+ conditions".
Var label conds1x_3 "(D) Ungrouped chapters and all conds counted: 3+ conditions".
miss vals conds1x_2 conds1x_3 (lo thru -1).

*Breakdown of change in definition.

miss vals conds1x ().
Compute MMNew_ST1=-99.
if (conds1x=1 and condcnt=0) MMNew_ST1=3.
if (conds1x GE 3) and (condcnt LT conds1x) MMNew_ST1=5.
if (conds1x GE 2 and condcnt LT 2) MMNew_ST1=4.
if conds1x=condcnt and condcnt=0 MMNew_ST1=0.
if conds1x=condcnt and condcnt=1 MMNew_ST1=1.
if conds1x=condcnt and condcnt GE 2 MMNew_ST1=2.
if conds1x lt 1 MMNew_ST1=conds1x.
exe.
var label MMNew_ST1 "(D) New MM measure (ungrouped/all counted) compared with
original (grouped)".
val labels MMNew_ST1
0 "No change: 0 conditions"
1 "No change: 1 condition"
2 "No change: >1 condition (MM)"
3 "From 0 conditions to 1"
4 "From 0 or 1 to >1 (newly MM)"
5 "From >1 to >2 (already MM)".
```

Stage 2: counting other health problems

Counting the conditions

```
count OHP_Cancer= HNCode1 HNCode2 HNCode3 (1).
count OHP_Diabetes= HNCode1 HNCode2 HNCode3 (2).
count OHP_OthEndc= HNCode1 HNCode2 HNCode3 (3).
count OHP_Psych= HNCode1 HNCode2 HNCode3 (4).
count OHP_LearnD= HNCode1 HNCode2 HNCode3 (5).
count OHP_Epileps= HNCode1 HNCode2 HNCode3 (6).
count OHP_Migraine= HNCode1 HNCode2 HNCode3 (7).
count OHP_OthNerv= HNCode1 HNCode2 HNCode3 (8).
count OHP_BadEyes= HNCode1 HNCode2 HNCode3 (9).
count OHP_OthEyes= HNCode1 HNCode2 HNCode3 (10).
count OHP_Deaf= HNCode1 HNCode2 HNCode3 (11).
count OHP_Tinnit= HNCode1 HNCode2 HNCode3 (12).
count OHP_Meniere= HNCode1 HNCode2 HNCode3 (13).
count OHP_OthEars= HNCode1 HNCode2 HNCode3 (14).
count OHP_Stroke= HNCode1 HNCode2 HNCode3 (15).
count OHP_MI= HNCode1 HNCode2 HNCode3 (16).
count OHP_HBP= HNCode1 HNCode2 HNCode3 (17).
count OHP_OthHrt= HNCode1 HNCode2 HNCode3 (18).
count OHP_Piles= HNCode1 HNCode2 HNCode3 (19).
```

```
count OHP_Varic= HNCode1 HNCode2 HNCode3 (20).
count OHP_OthBlod= HNCode1 HNCode2 HNCode3 (21).
count OHP_Bronch= HNCode1 HNCode2 HNCode3 (22).
count OHP_Asthma= HNCode1 HNCode2 HNCode3 (23).
count OHP_Hayf= HNCode1 HNCode2 HNCode3 (24).
count OHP_OthResp= HNCode1 HNCode2 HNCode3 (25).
count OHP_Ulcer= HNCode1 HNCode2 HNCode3 (26).
count OHP_OthDig= HNCode1 HNCode2 HNCode3 (27).
count OHP_Bowel= HNCode1 HNCode2 HNCode3 (28).
count OHP_Mouth= HNCode1 HNCode2 HNCode3 (29).
count OHP_Kidney= HNCode1 HNCode2 HNCode3 (30).
count OHP_UTI= HNCode1 HNCode2 HNCode3 (31).
count OHP_OthBlad= HNCode1 HNCode2 HNCode3 (32).
count OHP_Reprod= HNCode1 HNCode2 HNCode3 (33).
count OHP_Arthritis= HNCode1 HNCode2 HNCode3 (34).
count OHP_BackP= HNCode1 HNCode2 HNCode3 (35).
count OHP_OthMusc= HNCode1 HNCode2 HNCode3 (36).
count OHP_infect = HNCode1 HNCode2 HNCode3 (37).
count OHP_Blood= HNCode1 HNCode2 HNCode3 (38).
count OHP_skin= HNCode1 HNCode2 HNCode3 (39).
count OHP_Other= HNCode1 HNCode2 HNCode3 (40).
count OHP_unclass= HNCode1 HNCode2 HNCode3 (41).
count OHP_Cured= HNCode1 HNCode2 HNCode3 (42).

*Make a summary DV of info.
Recode HNote (-1, 1=1) (2,3=2) into Anyoth.
exe.
var label anyoth "(D) Whether mentioned another health problem".
val labs anyoth 1"No (not mentioned, just repeated)" 2 "Yes - new condition mentioned".

miss vals hnotask  HNote ().
if anyoth=1 OHP_cancer = -1 .
if anyoth=1 OHP_Diabetes = -1 .
if anyoth=1 OHP_OthEndc = -1 .
if anyoth=1 OHP_Psych = -1 .
if anyoth=1 OHP_LearnD = -1 .
if anyoth=1 OHP_Epileps = -1 .
if anyoth=1 OHP_Migraine = -1 .
if anyoth=1 OHP_OthNerv = -1 .
if anyoth=1 OHP_BadEyes = -1 .
if anyoth=1 OHP_OthEyes = -1 .
if anyoth=1 OHP_Deaf = -1 .
if anyoth=1 OHP_Tinnit = -1 .
if anyoth=1 OHP_Meniere = -1 .
if anyoth=1 OHP_OthEars = -1 .
if anyoth=1 OHP_Stroke = -1 .
if anyoth=1 OHP_MI = -1 .
if anyoth=1 OHP_HBP = -1 .
if anyoth=1 OHP_OthHrt = -1 .
if anyoth=1 OHP_Piles = -1 .
```

```
if anyoth=1 OHP_Varic = -1 .
if anyoth=1 OHP_OthBlod = -1 .
if anyoth=1 OHP_Bronch = -1 .
if anyoth=1 OHP_Asthma = -1 .
if anyoth=1 OHP_Hayf = -1 .
if anyoth=1 OHP_OthResp = -1 .
if anyoth=1 OHP_Ulcer = -1 .
if anyoth=1 OHP_OthDig = -1 .
if anyoth=1 OHP_Bowel = -1 .
if anyoth=1 OHP_Mouth = -1 .
if anyoth=1 OHP_Kidney = -1 .
if anyoth=1 OHP_UTI = -1 .
if anyoth=1 OHP_OthBlad = -1 .
if anyoth=1 OHP_Reprod = -1 .
if anyoth=1 OHP_Arthritis = -1 .
if anyoth=1 OHP_BackP = -1 .
if anyoth=1 OHP_OthMusc = -1 .
if anyoth=1 OHP_infect = -1 .
if anyoth=1 OHP_Blood = -1 .
if anyoth=1 OHP_skin = -1 .
if anyoth=1 OHP_Other = -1 .
if anyoth=1 OHP_unclass = -1 .
if anyoth=1 OHP_Cured = -1 .
exe.

miss vals OHP_Cancer TO OHP_Cured (-1).

***Make binaries of these vars.
Recode  OHP_Cancer OHP_Diabetes OHP_OthEndc OHP_Psych OHP_LearnD OHP_Epileps
OHP_Migraine OHP_OthNerv OHP_BadEyes OHP_OthEyes OHP_Deaf OHP_Tinnit
OHP_Meniere OHP_OthEars OHP_Stroke OHP_MI OHP_HBP OHP_OthHrt OHP_Piles
OHP_Varic OHP_OthBlod OHP_Bronch OHP_Asthma OHP_Hayf OHP_OthResp OHP_Ulcer
OHP_OthDig OHP_Bowel OHP_Mouth OHP_Kidney OHP_UTI OHP_OthBlad OHP_Reprod
OHP_Arthritis OHP_BackP OHP_OthMusc OHP_infect OHP_Blood OHP_skin OHP_Other
OHP_unclass OHP_Cured (1 thru hi=1) (else=copy) into OHP_Cancer2 OHP_Diabetes2
OHP_OthEndc2 OHP_Psych2 OHP_LearnD2 OHP_Epileps2 OHP_Migraine2 OHP_OthNerv2
OHP_BadEyes2 OHP_OthEyes2 OHP_Deaf2 OHP_Tinnit2 OHP_Meniere2 OHP_OthEars2
OHP_Stroke2 OHP_MI2 OHP_HBP2 OHP_OthHrt2 OHP_Piles2 OHP_Varic2 OHP_OthBlod2
OHP_Bronch2 OHP_Asthma2 OHP_Hayf2 OHP_OthResp2 OHP_Ulcer2 OHP_OthDig2
OHP_Bowel2 OHP_Mouth2 OHP_Kidney2 OHP_UTI2 OHP_OthBlad2 OHP_Reprod2
OHP_Arthritis2 OHP_BackP2 OHP_OthMusc2 OHP_infect2 OHP_Blood2 OHP_skin2
OHP_Other2 OHP_unclass2 OHP_Cured2.
exe.
val labs OHP_cancer2 TO OHP_cured2 1 "Has condition" 0 "Does not" -1 "Missing".


**Then count across conditions.
count numoth1 =  OHP_Cancer OHP_Diabetes OHP_OthEndc OHP_Psych OHP_LearnD
OHP_Epileps OHP_Migraine OHP_OthNerv OHP_BadEyes OHP_OthEyes OHP_Deaf
OHP_Tinnit OHP_Meniere OHP_OthEars OHP_Stroke OHP_MI OHP_HBP OHP_OthHrt
```

```
OHP_Piles OHP_Varic OHP_OthBlod OHP_Bronch OHP_Asthma OHP_Hayf OHP_OthResp
OHP_Ulcer OHP_OthDig OHP_Bowel OHP_Mouth OHP_Kidney OHP_UTI OHP_OthBlad
OHP_Reprod OHP_Arthritis OHP_BackP OHP_OthMusc OHP_infect OHP_Blood OHP_skin
OHP_Other OHP_unclass (1).
if anyoth=1 numoth1=0.
exe.

count numoth2 =  OHP_Cancer OHP_Diabetes OHP_OthEndc OHP_Psych OHP_LearnD
OHP_Epileps OHP_Migraine OHP_OthNerv OHP_BadEyes OHP_OthEyes OHP_Deaf
OHP_Tinnit OHP_Meniere OHP_OthEars OHP_Stroke OHP_MI OHP_HBP OHP_OthHrt
OHP_Piles OHP_Varic OHP_OthBlod OHP_Bronch OHP_Asthma OHP_Hayf OHP_OthResp
OHP_Ulcer OHP_OthDig OHP_Bowel OHP_Mouth OHP_Kidney OHP_UTI OHP_OthBlad
OHP_Reprod OHP_Arthritis OHP_BackP OHP_OthMusc OHP_infect OHP_Blood OHP_skin
OHP_Other OHP_unclass (2).
if anyoth=1 numoth2=0.
exe.

count numoth3 =  OHP_Cancer OHP_Diabetes OHP_OthEndc OHP_Psych OHP_LearnD
OHP_Epileps OHP_Migraine OHP_OthNerv OHP_BadEyes OHP_OthEyes OHP_Deaf
OHP_Tinnit OHP_Meniere OHP_OthEars OHP_Stroke OHP_MI OHP_HBP OHP_OthHrt
OHP_Piles OHP_Varic OHP_OthBlod OHP_Bronch OHP_Asthma OHP_Hayf OHP_OthResp
OHP_Ulcer OHP_OthDig OHP_Bowel OHP_Mouth OHP_Kidney OHP_UTI OHP_OthBlad
OHP_Reprod OHP_Arthritis OHP_BackP OHP_OthMusc OHP_infect OHP_Blood OHP_skin
OHP_Other OHP_unclass (3).
if anyoth=1 numoth3=0.
exe.

var labels numoth1 "(D) Number of other conditions (counting across conditions)".
var labels numoth2 "(D) Number with 2 of the same other conditions".
var labels numoth3 "(D) Number with 3 of the same other conditions".

*Total number of other conditions.

compute tot_numoth=0.
if anyoth=1 tot_numoth=0.
if numoth1=1 tot_numoth=tot_numoth+1.
if numoth1=2 tot_numoth=tot_numoth+2.
if numoth1=3 tot_numoth=tot_numoth+3.
if numoth2=1 tot_numoth=tot_numoth+2.
if numoth3=1 tot_numoth=tot_numoth+3.
exe.

if tot_numoth=0 and anyoth=2 and OHP_cured=0 tot_numoth=1.
exe.
var labels tot_numoth "(D) Total number of other conditions".
```

Adding other health problems to the long-term condition count

All other problems

```
miss vals conds1x tot_numoth () .
compute conds1x_OHP=-99.
if tot_numoth=1  conds1x_OHP=conds1x+1.
if tot_numoth=2  conds1x_OHP=conds1x+2.
if tot_numoth=3  conds1x_OHP=conds1x+3.
if tot_numoth=0  conds1x_OHP=conds1x.
exe.
var label conds1x_OHP "(D) Number of conditions, inc all other problems".
```

All other problems if general health <good

```
weight off.
miss vals conds1x tot_numoth () .
compute conds1x_OHPB=-99.
if tot_numoth=1  conds1x_OHPB=conds1x+1.
if tot_numoth=2  conds1x_OHPB=conds1x+2.
if tot_numoth=3  conds1x_OHPB=conds1x+3.
if tot_numoth=0  conds1x_OHPB=conds1x.
if genhelf2=1 conds1x_OHPB=conds1x.
exe.
VAR LABS conds1x_OHPB "(D) Number of conditions, inc other problems only if genhelf fair-
bad".
```

Summary measure of multiple conditions

All other problems

```
recode  conds1x_OHP (2 thru hi=2) (else=copy) into MMOHP.
exe.
var labels MMOHP "(D) 2 or more conditions, inc other health problems".
val labs MMOHP 0 "0 conditions" 1 "1 condition" 2 "2 or more".

miss vals MMOHP (lo thru -1).

*Breakdown of change in definition.

miss vals conds1x_OHP ().
Compute MMNew_ST2a=-99.
if (conds1x_OHP=1 and condcnt=0) MMNew_ST2a=3.
if (conds1x_OHP GE 3) and (condcnt LT conds1x_OHP) MMNew_ST2a=5.
if (conds1x_OHP GE 2 and condcnt LT 2) MMNew_ST2a=4.
if conds1x_OHP=condcnt and condcnt=0 MMNew_ST2a=0.
if conds1x_OHP=condcnt and condcnt=1 MMNew_ST2a=1.
```

```
if conds1x_OHP=condcnt and condcnt GE 2 MMNew_ST2a=2.
if conds1x_OHP lt 1 MMNew_ST2a=conds1x_OHP.
exe.
var label MMNew_ST2a "(D) New MM measure (all OHPs added) compared with original
(grouped)".
val labels MMNew_ST2a
0 "No change: 0 conditions"
1 "No change: 1 condition"
2 "No change: >1 condition (MM)"
3 "From 0 conditions to 1"
4 "From 0 or 1 to >1 (newly MM)"
5 "From >1 to >2 (already MM)".
fre MMNew_ST2a.
```

All other problems if general health <good

```
recode  conds1x_OHPB (2 thru hi=2) (else=copy) into MMOHPB.
exe.
var labels MMOHPB "(D) 2 or more conditions, inc other health problems only if genhelf
fair-bad".
val labs MMOHPB 0 "0 conditions" 1 "1 condition" 2 "2 or more".

miss vals MMOHPB (lo thru -1).

*Breakdown of change in definition.
Compute MMNew_ST2b=-99.
if (conds1x_OHPB=1 and condcnt=0) MMNew_ST2b=3.
if (conds1x_OHPB GE 3) and (condcnt LT conds1x_OHPB) MMNew_ST2b=5.
if (conds1x_OHPB GE 2 and condcnt LT 2) MMNew_ST2b=4.
if conds1x_OHPB=condcnt and condcnt=0 MMNew_ST2b=0.
if conds1x_OHPB=condcnt and condcnt=1 MMNew_ST2b=1.
if conds1x_OHPB=condcnt and condcnt GE 2 MMNew_ST2b=2.
if conds1x_OHPB lt 1 MMNew_ST2b=conds1x_OHPB.
exe.
var label MMNew_ST2b "(D) New MM measure (OHPs added if health <good) compared
with original (grouped)".
val labels MMNew_ST2b
0 "No change: 0 conditions"
1 "No change: 1 condition"
2 "No change: >1 condition (MM)"
3 "From 0 conditions to 1"
4 "From 0 or 1 to >1 (newly MM)"
5 "From >1 to >2 (already MM)".
```

Stage 3: undeclared hypertension, diabetes, MI & stroke

Identifying undeclared conditions

Hypertension

```
miss vals CURRBP HBP2 ().
compute HBP_UD=-99.
if CURRBP=1 and HBP2=0 HBP_UD=1.
if CURRBP=1 and HBP2=1 HBP_UD=0.
if CURRBP=2 HBP_UD=0.
if CURRBP LT 0 | HBP2 LT 0 HBP_UD=-1.
exe.
Var lab HBP_UD "(D) Undeclared hypertension".
miss vals HBP_UD (-1).
```

Diabetes

```
miss vals diabete2 Diabetes2 ().
compute DIA_UD=-99.
if diabete2=1 and Diabetes2 =0 DIA_UD=1.
if diabete2=1 and Diabetes2 =1 DIA_UD=0.
if diabete2=2 DIA_UD=0.
if diabete2 LT 0 | Diabetes2  LT 0 DIA_UD=-1.
exe.
Var lab DIA_UD "(D) Undeclared diabetes".
miss vals DIA_UD (-1).
```

MI / angina

```
*This requires a combined measure of any MI / angina.

miss vals heartdef angidef ().
compute MIAng_dr=-99.
if angidef=1 or  heartdef=1 MIAng_dr=1.
if angidef=2 and heartdef=2 MIAng_dr=2.
if angidef=1 and (heartdef LT 0 ) MIAng_dr=1.
if heartdef=1 and (angidef LT 0 ) MIAng_dr=1.
if angidef=2 and (heartdef LT 0 ) MIAng_dr=2.
if heartdef=2 and (angidef LT 0 ) MIAng_dr=2.
exe.
var lab MIAng_dr "(D) Whether had MI or angina".

*And requires a measure of whether MI / angina was recent.

miss vals  recangi recheart ().
compute MIAngRec_dr=-99.
if MIAng_dr=1 and (recangi=1 or  recheart=1) MIAngRec_dr=1.
if MIAng_dr=1 and (recangi=2 and recheart=2) MIAngRec_dr=2.
```

```
if MIAng_dr=1 and (recangi=-1 and recheart=2)  MIAngRec_dr=2.
if MIAng_dr=1 and (recangi=2 and recheart=-1)  MIAngRec_dr=2.
if MIAng_dr=2 MIAngRec_dr=3.
exe.
var lab MIAngRec_dr "(D) Whether had MI or angina in past year".

*This is the measure of undeclared recent MI/angina.

miss vals MIAngrec_dr MI2 ().
compute MIA_UD=-99.
if MIAngrec_dr=1 and MI2  =0 MIA_UD=1.
if MIAngrec_dr=1 and MI2  =1 MIA_UD=0.
if MIAngrec_dr=0 MIA_UD=0.
if MIAngrec_dr=3 MIA_UD=0.
if MIAngrec_dr LT 0 | MI2  LT 0 MIA_UD=-1.
exe.
Var lab MIA_UD "(D) Undeclared MI/angina".
fre MIA_UD.
miss vals MIA_UD (-1).
cro MIA_UD by MIAngrec_dr by MI2.
```

Stroke

```
miss vals RECSTRO3 STROKE2 ().
compute STR_UD=-99.
if RECSTRO3=1 and STROKE2=0 STR_UD=1.
if RECSTRO3=1 and STROKE2=1 STR_UD=0.
if RECSTRO3=0 STR_UD=0.
if RECSTRO3 LT 0 | STROKE2 LT 0 STR_UD=-1.
exe.
Var lab STR_UD "(D) Undeclared recent stroke".
miss vals STR_UD ().
```

Adding undeclared conditions to the long-term condition count

```
compute conds1x_def2=conds1x.
if HBP_UD=1 conds1x_def2=conds1x_def2+1.
if DIA_UD=1 conds1x_def2=conds1x_def2+1.
if MIA_UD=1 conds1x_def2=conds1x_def2+1.
if STR_UD=1 conds1x_def2=conds1x_def2+1.

exe.
var labels conds1x_def2 "(D) Number of conditions, undeclared HBP, diabetes, MI/angina &
stroke".
```

Summary measure of multiple conditions

```
recode  conds1x_def2 (2 thru hi=2) (else=copy) into MMDef2.
exe.
var labels MMDef2 "(D) 2 or more conditions, inc undeclared HBP, diabetes, MI/angina &
stroke".
val labs MMDef2 0 "0 conditions" 1 "1 condition" 2 "2 or more".

*Breakdown of change in definition.

miss vals conds1x_def2 ().
Compute MMNew_ST3=-99.
if (conds1x_def2=1 and condcnt=0) MMNew_ST3=3.
if (conds1x_def2 GE 3) and (condcnt LT conds1x_def2) MMNew_ST3=5.
if (conds1x_def2 GE 2 and condcnt LT 2) MMNew_ST3=4.
if conds1x_def2=condcnt and condcnt=0 MMNew_ST3=0.
if conds1x_def2=condcnt and condcnt=1 MMNew_ST3=1.
if conds1x_def2=condcnt and condcnt GE 2 MMNew_ST3=2.
if conds1x_def2 lt 1 MMNew_ST3=conds1x_def2.
exe.
var label MMNew_ST3 "(D) New MM measure (undeclared conds) compared with original
(grouped)".
val labels MMNew_ST3
0 "No change: 0 conditions"
1 "No change: 1 condition"
2 "No change: >1 condition (MM)"
3 "From 0 conditions to 1"
4 "From 0 or 1 to >1 (newly MM)"
5 "From >1 to >2 (already MM)".
```

Creating the new measure

Counting all the conditions

```
*Start with the condition count that includes all long-term conditions and other health
problems if general health <good, and add the newly identified CVD conditions.

compute conds1x_final=conds1x_OHPB.
if HBP_UD=1 conds1x_final = conds1x_final +1.
if DIA_UD=1 conds1x_final = conds1x_final +1.
if MIA_UD=1 conds1x_final = conds1x_final +1.
if STR_UD=1 conds1x_final = conds1x_final +1.
exe.
var labels conds1x_final "(D) Number of conditions, inc OHP (if genhelf fair-bad),
undeclared HBP, diabetes & MI/angina & stroke".
```

New summary measure of multiple conditions

```
recode  conds1x_final (2 thru hi=2) (else=copy) into MMDef_final.
exe.
var labels MMDef_final "(D) 2 or more conditions, inc OHP (if genhelf fair-bad), undeclared
HBP, diabetes & MI/angina & stroke".
val labs MMDef_final 0 "0 conditions" 1 "1 condition" 2 "2 or more".
```

Breakdown of change in definition.

```
miss vals conds1x_final ().
Compute MMNew_fin=-99.
if (conds1x_final=1 and condcnt=0) MMNew_fin=3.
if (conds1x_final GE 3) and (condcnt LT conds1x_final) MMNew_fin=5.
if (conds1x_final GE 2 and condcnt LT 2) MMNew_fin=4.
if conds1x_final=condcnt and condcnt=0 MMNew_fin=0.
if conds1x_final=condcnt and condcnt=1 MMNew_fin=1.
if conds1x_final=condcnt and condcnt GE 2 MMNew_fin=2.
if conds1x_final lt 1 MMNew_fin=conds1x_final.
exe.
var label MMNew_fin "(D) New MM measure (Final Def) compared with original
(grouped)".
val labels MMNew_fin
0 "No change: 0 conditions"
1 "No change: 1 condition"
2 "No change: >1 condition (MM)"
3 "From 0 conditions to 1"
4 "From 0 or 1 to >1 (newly MM)"
5 "From >1 to >2 (already MM)".
fre MMNew_fin.
```

With limiting conditions identified

```
miss vals mmdef_final ().
compute MMDef_finallim=-99.
if MMDef_final=0 MMDef_finallim =0.
if MMDef_final=1 and Limitill GT 1 MMDef_finallim =1.
if MMDef_final=1 and Limitill=1 MMDef_finallim =2.
if MMDef_final=2 and Limitill GT 1 MMDef_finallim =3.
if MMDef_final=2 and Limitill=1 MMDef_finallim =4.
if MMDef1_finalLT 0 MMDef_finallim =MMDef_final.
exe.
var lab MMDef_finallim "(D) Final definition with limiting conditions identified".
val labs MMDef_finallim 0 "No conditions" 1 "1 non-limiting condition" 2 "1 limiting
condition" 3 "2 or more conds, 0 limiting" 4 "2 or more conditions, at least 1 limiting".
fre MMDef1Lim.
```

Additional variables for 1998 survival analysis (Chapter 5)

Hypertension

*Uses the information about undeclared hypertension and condition count (ungrouped chapters, all conditions counted).

```
miss vals hbp_ud conds1x_2 ().
compute MMNot_HBP2=-99.
if conds1x_2 =1 and HBP_UD=1 MMNot_HBP2=1.
```

```
if conds1x_2 =1 and HBP_UD le 0 MMNot_HBP2=2.
if conds1x_2 =2 and HBP_UD=1 MMNot_HBP2=3.
if conds1x_2 =2 and HBP_UD le 0 MMNot_HBP2=4.
if conds1x_2 =0 and HBP_UD=1 MMNot_HBP2=5.
if conds1x_2 =0 and HBP_UD le 0 MMNot_HBP2=6.
if conds1x_2 lt 0 MMNot_HBP2=conds1x_2.
exe.

var label MMNot_HBP2 "(D) MM & UDH".
val labels MMNot_HBP2
1 "UDH & 1 condition" 2 "No UDH & 1 condition" 3 "UDH & >1 condition" 4 "No UDH & >1
conditions" 5 "UDH & 0 conditions" 6 "No UDH / 0 conditions".
```

Obesity

```
compute MMObese=-99.
if conds1x_2=2 and BMIvg4 =4 MMObese=1.
if conds1x_2=1 and BMIvg4 =4 MMObese=2.
if conds1x_2=0 and BMIvg4 =4 MMObese=3.
if conds1x_2=2 and BMIvg4 LT 4 MMObese=4.
if conds1x_2=1 and BMIvg4 LT 4 MMObese=5.
if conds1x_2=0 and BMIvg4 LT 4 MMObese=6.
If BMIvg4 LT 1 MMObese=-1.
exe.

Var lab MMObese "(D) MM status (ungrouped & all counted) and obesity".
val labs MMObese -1 “No BMI” 1 "MM & obese" 2 "1 condition & obese" 3 "0 conditions &
obese" 4 "MM & not obese" 5 "1 condition & not obese" 6 "0 conditions & not obese".
```

Other health problems (all included)

```
compute OHPMM=-99.
if conds1x_2=2 and hnotask=1 OHPMM=1.
if conds1x_2=1 and hnotask=1 OHPMM=2.
if conds1x_2=0 and hnotask=1 OHPMM=3.
if conds1x_2=2 and hnotask=2 OHPMM=4.
if conds1x_2=1 and hnotask=2 OHPMM=5.
if conds1x_2=0 and hnotask=2 OHPMM=6.
exe.

Var lab OHPMM "(D) MM status (ungrouped & all counted) and OHP".
val labs OHPMM 1 "MM & OHP" 2 "1 condition & OHP" 3 "0 conditions & OHP" 4 "MM & no
OHP" 5 "1 condition & no OHP" 6 "0 conditions & no OHP".
fre OHPMM.
```

Other health problems (if general health <good)

```
compute OHPBMM=-99.
if conds1x_2=2 and hnotask=1 and genhelf GT 2 OHPBMM=1.
if conds1x_2=1 and hnotask=1 and genhelf GT 2 OHPBMM=2.
```

```
if conds1x_2=0 and hnotask=1 and genhelf GT 2 OHPBMM=3.
if conds1x_2=2 and (hnotask=2 OR (hnotask=1 and genhelf LT 3)) OHPBMM=4.
if conds1x_2=1 and (hnotask=2 OR (hnotask=1 and genhelf LT 3)) OHPBMM=5.
if conds1x_2=0 and (hnotask=2 OR (hnotask=1 and genhelf LT 3)) OHPBMM=6.
exe.

Var lab OHPBMM "(D) MM status (ungrouped & all counted) and OHP if genhelf <good".
val labs OHPBMM 1 "MM & OHP" 2 "1 condition & OHP" 3 "0 conditions & OHP" 4 "MM &
no OHP" 5 "1 condition & no OHP" 6 "0 conditions & no OHP".
fre OHPBMM.
```

Additional variables for 1998 survival analysis (Chapter 6)

GHQ12

*Variable to identify people with GHQ12 score >=4, in combination with the final multiple conditions definition (called MMDef1 in 1998 file).

```
miss vals MMDef1 ghqg2 ().
compute MMDef1_GHQ=-99.
if mmdef1=0 and (ghqg2=1 or ghqg2=2) MMDef1_GHQ=0.
if mmdef1=0 and (ghqg2=3) MMDef1_GHQ=1.
if mmdef1=1 and (ghqg2=1 or ghqg2=2) MMDef1_GHQ=2.
if mmdef1=1 and (ghqg2=3) MMDef1_GHQ=3.
if mmdef1=2 and (ghqg2=1 or ghqg2=2) MMDef1_GHQ=4.
if mmdef1=2 and (ghqg2=3) MMDef1_GHQ=5.
if mmdef1 LT 0 or GHQg2 LT 0 MMDef1_GHQ=-1.
exe.

var lab mmdef1_ghq "(D) MM measure with GHQ scores integrated".
val labs mmdef1_ghq
-1 "Missing data" 0 "No conditions, GHQ <4" 1 "No conditions, GHQ >=4" 2 "1 condition,
GHQ <4" 3 "1 condition, GHQ >=4" 4 "2 conditions, GHQ <4" 5 "2 conditions, GHQ >=4".
miss vals mmdef1_ghq (-1).
```

Limiting conditions

Used the variable MMDef_FinalLim (syntax above).

Carstairs deprivation

*Variable to identify people living in the Carstairs most deprived quartile, in combination with the final multiple conditions definition (called MMDef1 in 1998 file).

```
miss vals MMDef1 carstg4 ().
compute MMDef1_car=-99.
if mmdef1=0 and (carstg4 ne 4) MMDef1_car=0.
if mmdef1=0 and (carstg4=4) MMDef1_car=1.
if mmdef1=1 and (carstg4 ne 4) MMDef1_car=2.
if mmdef1=1 and (carstg4=4) MMDef1_car=3.
if mmdef1=2 and (carstg4 ne 4) MMDef1_car=4.
```

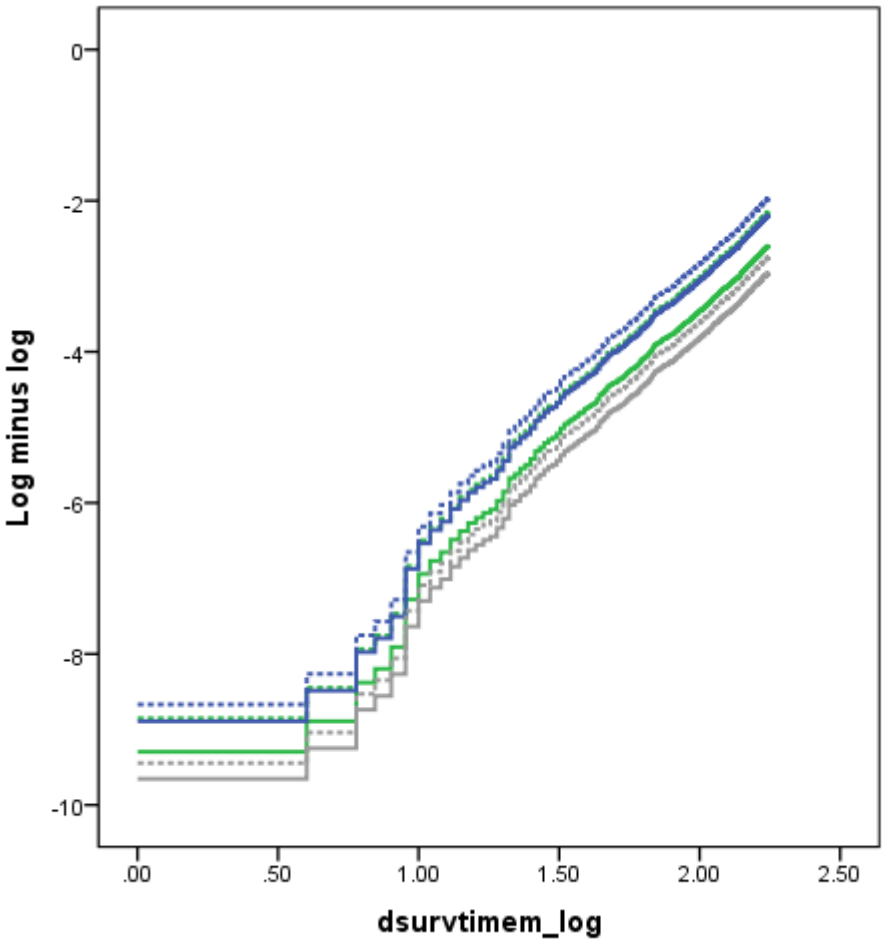
```
if mmdef1=2 and (carstg4=4) MMDef1_car=5.
if mmdef1 LT 0 or carstg4 LT 0 MMDef1_car=-1.
exe.

var lab mmdef1_car "(D) MM measure with Carstairs integrated".
val labs mmdef1_car
0 "No conditions, not deprived" 1 "No conditions, deprived" 2 "1 condition, not deprived" 3
"1 condition, deprived" 4 "2 conditions, not deprived" 5 "2 conditions, deprived".
miss vals mmdef1_car (-1).
```

Appendix G: Supplementary material Chapter 5

Undeclared hypertension survival analysis

Log-log plots

Figure G1: Log-log plot of undeclared hypertension and survival (to illustrate **non**-proportional hazards in survival analysis presented in Chapter 5, Figure 5.3)



Sample sizes

Table G1: Unweighted sample sizes for survival analysis of undeclared hypertension

	Events	**Censored**	**Total**
1 condition, & UDH	87	127	214
1 condition, no UDH	310	1685	1995
2 or more conditions, & UDH	106	117	223
2 or more conditions, no UDH	364	800	1164
No conditions, & UDH	57	166	223
No conditions, no UDH	334	4152	4486

Other health problems survival analysis

Sample sizes

Table G2: Unweighted sample sizes for survival analysis of other health problems

	Events	**Censored**	**Total**
1 condition, & OHP	66	227	293
1 condition, no OHP	331	1585	1916
2 or more conditions, & OHP	90	148	238
2 or more conditions, no OHP	380	769	1149
No conditions, & OHP	61	560	621
No conditions, no OHP	330	3758	4088

Obesity survival analysis

Sample sizes

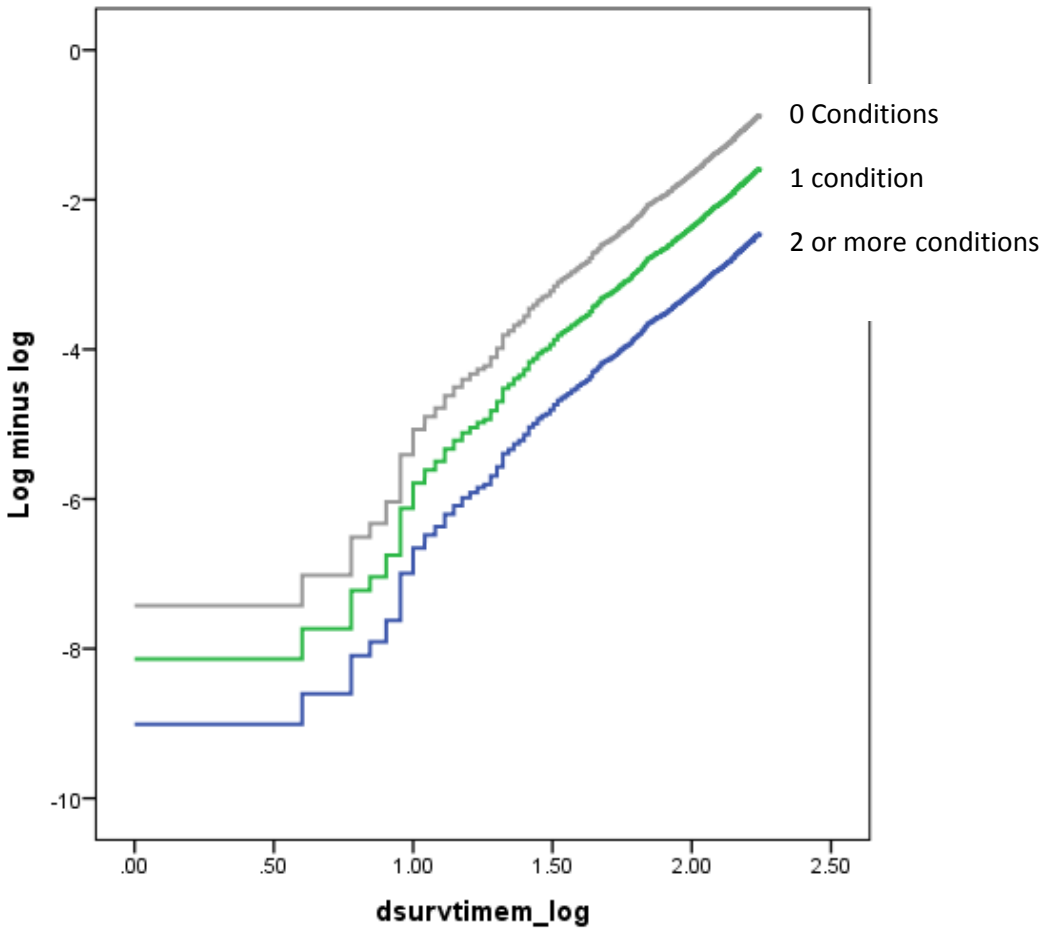
Table G3: Unweighted sample sizes for survival analysis of BMI $\geq$30

	Events	**Censored**	**Total**
1 condition, & BMI $\geq$30	76	393	469
1 condition, BMI <30	253	1257	1510
2 or more conditions, & BMI $\geq$30	139	280	419
2 or more conditions, BMI <30	257	537	794
No conditions, & BMI $\geq$30	81	700	781
No conditions, BMI <30	275	3318	3593

Original definition of multiple conditions survival analysis

Log-log plots

Figure G2: Log-log plot of original multiple conditions definition and survival (to illustrate proportional hazards in survival analysis presented in Chapter 5, Figure 5.10)



Sample sizes

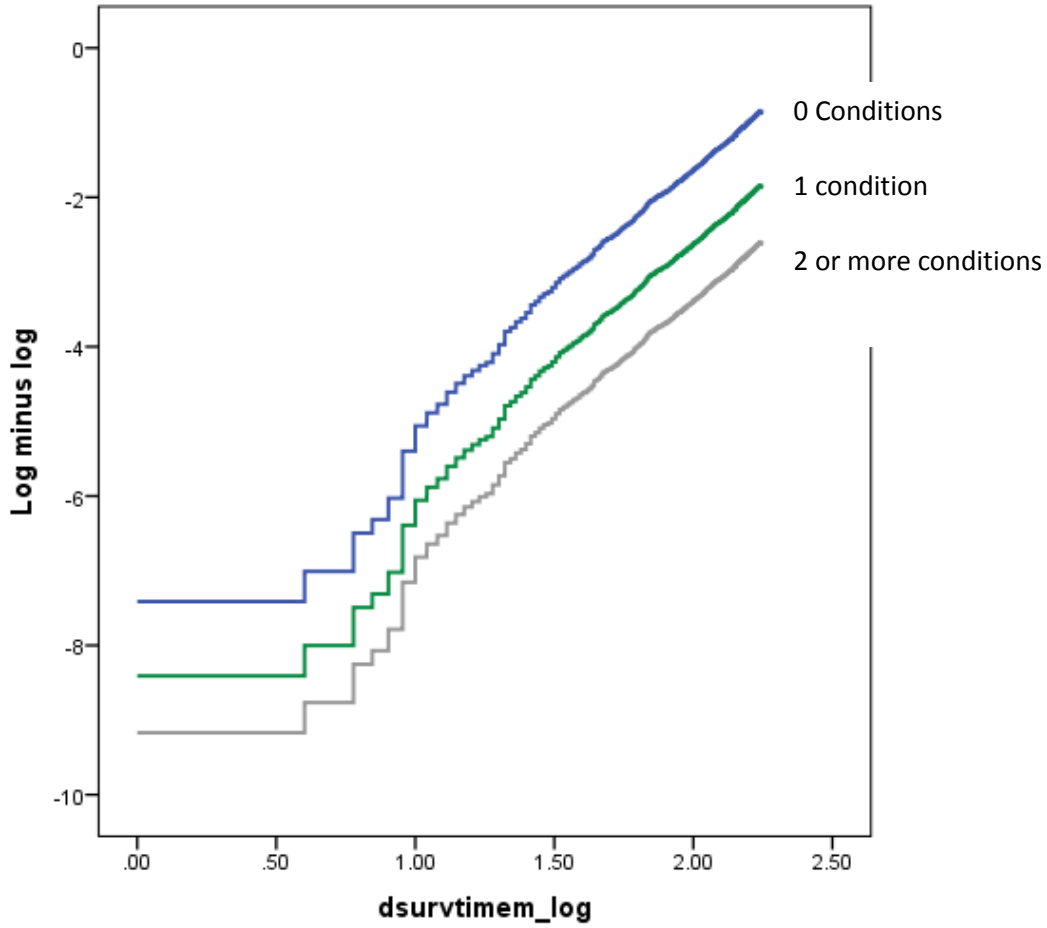
Table G4: Unweighted samples for survival analysis (original multiple conditions definition)

	Events	**Censored**	**Total**
No conditions	394	4326	4720
1 condition	438	1907	2345
2 or more conditions	426	814	1240

New definition of multiple conditions survival analysis

Log-log plots

Figure G3: Log-log plot of new definition of multiple conditions and survival (to illustrate proportional hazards in survival analysis presented in Chapter 5, Figure 5.11)



Sample sizes

Table G5: Unweighted sample sizes for survival analysis of new definition of multiple conditions

	Events	Censored	Total
No conditions	318	4069	4387
1 condition	320	1831	2151
2 or more conditions	620	1147	1767

Estimated odds ratios for having multiple conditions

Table G6: Unadjusted and adjusted odds ratios for having multiple conditions by sex and SIMD quintile

Multiple conditions (>1)	Unadjusted OR	95% CI[a]	Age-group adjusted OR	95% CI[a]
Sex (p<0.001)				
Men (reference category)	1.0		1.0	
Women	1.2	1.2-1.3	1.1	1.1-1.2
SIMD quintile (p<0.001)				
5th least deprived (reference category)	1.0		1.0	
4th	1.2 [p=0.002]	1.1-1.3	1.2	1.1-1.3
3rd	1.5	1.4-1.6	1.6	1.4-1.8
2nd	1.7	1.5-1.8	2.0	1.8-2.2
1st most deprived	2.1	1.9-2.2	2.8	2.5-3.1

[a]p value for all ORs <0.001, unless stated otherwise.

Appendix H: Sample sizes for Chapter 6 charts

Figure 6.1 Prevalence of a BMI in the overweight range, and prevalence of being an ex-smoker, by condition number (0, 1, 2 or more) and SIMD quintile
&
Figure 6.2 Prevalence of eating <2 portions of fruit and vegetables per day, and prevalence of current smoking, by condition number (0, 1, 2 or more) and SIMD quintile
&
Figure 6.3 Prevalence of being active for <30 minutes per week, and prevalence of a BMI in the obese range, by condition number (0, 1, 2 or more) and SIMD quintile

	BMI overweight / obese	Current / Ex-smokers	Physically inactive	<2 portions of fruit & veg p/day
SIMD least deprived quintile				
No conditions	2366	2736	2752	2757
One condition	1048	1227	1228	1230
Two or more conditions	859	1092	1092	1092
4th quintile				
No conditions	2844	3251	3268	3273
One condition	1429	1661	1663	1665
Two or more conditions	1235	1546	1546	1551
3rd quintile				
No conditions	2441	2843	2857	2860
One condition	1281	1492	1494	1497
Two or more conditions	1359	1741	1745	1745
2nd quintile				
No conditions	2105	2425	2443	2445
One condition	1092	1272	1274	1276
Two or more conditions	1326	1759	1759	1763
SIMD most deprived quintile				
No conditions	1905	2250	2270	2276
One condition	1056	1291	1299	1301
Two or more conditions	1526	2039	2036	2041

Figure 6.4 Prevalence of GHQ12 score ≥4 and low wellbeing (SWEWMBS >1 SD below mean), by condition number (0, 1, 2 or more) and SIMD quintile

	GHQ12 score ≥4	SWEWMBS >1 SD below mean
SIMD least deprived quintile		
No conditions	2563	2557
One condition	1147	1143
Two or more conditions	987	985
4th quintile		
No conditions	3042	3034
One condition	1536	1540
Two or more conditions	1391	1394
3rd quintile		
No conditions	2657	2657
One condition	1381	1375
Two or more conditions	1569	1571
2nd quintile		
No conditions	2256	2253
One condition	1174	1175
Two or more conditions	1549	1556
SIMD most deprived quintile		
No conditions	2062	2070
One condition	1138	1147
Two or more conditions	1759	1776

Figure 6.5 Forest plot of risks associated with having multiple conditions (2 or more versus 0 or 1) in men, adjusted for age and SIMD

	Current or ex-smoker	Overweight / obese	<2 F&V portions / day	<30 mins activity / wk	Low wellbeing
Has risk factor	**6601**	**4566 / 3151**	**4030**	**4147**	**1581**
Reference category	**5844**	**2847**	**8485**	**8351**	**9764**
Age group					
16-24	1051	987	1100	1097	1003
25-34	1538	1373	1543	1542	1422
35-44	2000	1758	2004	2003	1850
45-54	2296	2003	2302	2298	2115
55-64	2254	1919	2256	2254	2077
65-74	1967	1678	1969	1968	1767
75+	1339	970	1341	1336	1111
SIMD quintile					
5th least deprived	2224	1938	2234	2231	2054
4th	2870	2520	2887	2885	2648
3rd	2666	2292	2679	2675	2443
2nd	2345	2014	2359	2354	2131
1st most deprived	2340	1924	2356	2353	2069

Figure 6.6 Forest plot of risks associated with having multiple conditions (2 or more versus 0 or 1) in women, adjusted for age and SIMD

	Current or ex-smoker	Overweight / obese	<2 F&V portions / day	<30 mins activity / wk	Low wellbeing
Has risk factor	**7519**	**4468 / 3947**	**4489**	**5704**	**1905**
Reference category	**8660**	**4544**	**11767**	**10524**	**12983**
Age group					
16-24	1405	1210	1453	1452	1351
25-34	2158	1745	2159	2156	2024
35-44	2816	2360	2821	2818	2651
45-54	2923	2473	2931	2926	2754
55-64	2803	2331	2807	2803	2602
65-74	2232	1824	2237	2234	2016
75+	1842	1241	1848	1839	1490
SIMD quintile					
5th least deprived	2830	2335	2884	2841	2631
4th	3588	2988	3602	3592	3320
3rd	3410	2789	3423	3421	3160
2nd	3111	2509	3125	3122	2853
1st most deprived	3240	2563	3262	3252	2924

Figure 6.7 Individual WEMWBS items by number of conditions (0-5 or more)
&
Figure 6.8 Individual SWEMWBS item mean scores by number of conditions (0-5 or more)
Note: total sample size varies by question (26489-26614), figures are presented for the lowest of the range

No conditions	12670
One	6444
Two	3593
Three	1973
Four	960
Five or more	849

Figure 6.9 Individual SWEMWBS item mean scores by number of conditions (0, 1, 2 or more)

No conditions	12670
One	6444
Two or more	7375

Figure 6.10 Prevalence of SWEMWBS >1 SD below mean, and >1 SD above mean, by condition number (0-5 or more)

No conditions	12571
One	6380
Two	3543
Three	1951
Four	947
Five or more	841

Figure 6.11 Prevalence of SWEMWBS >1 SD below mean, by age group and condition number (0, 1, 2 or more)

	16-24	**25-34**	**35-44**	**45-54**	**55-65**	**65-74**	**75+**
No conditions	1823	2483	2853	2488	1614	917	393
One	390	645	984	1267	1361	1042	691
Two or more	141	318	664	1114	1704	1834	1517

Figure 6.12 Prevalence of SWEMWBS score >1 SD below mean by age group and condition number (0-5 or more)
Note: sample sizes below 100 are emboldened

	16-44	**45-64**	**65+**
No conditions	7159	4102	1310
One	2019	2628	1733
Two	714	1386	1443
Three	259	738	954
Four	**81**	362	504
Five or more	**69**	332	440

Figure 6.13 Prevalence of SWEMWBS >1 SD below mean, by condition number (0, 1, 2 or more) and SIMD quintile

	SIMD 5th least deprived quintile	4th	3rd	2nd	SIMD 1st most deprived quintile
No conditions	2557	3034	2657	2253	2070
One	1143	1540	1375	1175	1147
Two	985	1394	1571	1556	1776

Figure 6.14 Individual SWEMWBS item mean scores by SIMD quintile – among people with multiple conditions

&

Figure 6.15 Individual SWEMWBS item mean scores by SIMD quintile – among people with one condition

Note: total sample size varies by question (7375-7429 multiple conditions; 6444-6476 one condition), figures are presented for the lowest of the range

SIMD quintile	Multiple conditions	One condition
5th least deprived	997	1151
4th	1408	1555
3rd	1592	1390
2nd	1575	1186
1st most deprived	1803	1162

Figure 6.16 Prevalence of SWEMWBS score >1 SD below mean by condition number (0, 1 2 or more), age group and SIMD quintile

	16-44	45-64	65+
SIMD 5th least deprived quintile			
No conditions	1296	957	304
One condition	275	506	362
Two or more conditions	105	345	535
4th quintile			
No conditions	1616	1071	347
One condition	425	673	442
Two or more conditions	186	522	686
3rd quintile			
No conditions	1470	887	300
One condition	421	563	391
Two or more conditions	227	596	748
2nd quintile			
No conditions	1394	664	195
One condition	415	460	300
Two or more conditions	243	580	733
SIMD 1st most deprived quintile			
No conditions	1383	523	164
One condition	483	426	238
Two or more conditions	362	775	639

Figure 6.17 Prevalence of SWEMWBS >1 S D below mean by condition number (1, 2 or more), presence of a limiting condition and age group

	Non-limiting condition	Limiting condition
16-44		
One condition	1181	838
Two or more conditions	252	871
45-64		
One condition	1762	866
Two or more conditions	708	2110
65+		
One condition	1281	452
Two or more conditions	842	2499

Figure 6.18 Prevalence of SWEMWBS >1 SD below mean by condition number (1, 2 or more), presence of a limiting condition and SIMD quintile

	Non-limiting condition	Limiting condition
SIMD 5th least deprived quintile		
One condition	816	327
Two or more conditions	360	625
4th quintile		
One condition	1051	489
Two or more conditions	391	1003
3rd quintile		
One condition	924	451
Two or more conditions	400	1171
2nd quintile		
One condition	760	415
Two or more conditions	334	1222
SIMD 1st most deprived quintile		
One condition	673	474
Two or more conditions	317	1459

Figure 6.19 Prevalence of low levels of life satisfaction (scores of 0-5) by condition number (0, 1, 2 or more) and age group

	16-24	25-34	35-44	45-54	55-65	65-74	75+
No conditions	1972	2699	3059	2664	1729	1007	486
One	418	689	1046	1349	1453	1165	824
Two or more	154	338	710	1207	1872	2020	1856

Figure 6.20 Prevalence of SWEMWBS >1 SD below mean, by age group and condition number (0, 1, 2 or more) – original data
-Same as Figure 6.11 above

Figure 6.21 Prevalence of SWEMWBS >1 SD below mean, by age group and condition number (0, 1, 2 or more) – following multiple imputation of missing data

	16-24	25-34	35-44	45-54	55-65	65-74	75+
No conditions	1977	2674	3063	2671	1730	1009	486
One	421	690	1049	1352	1457	1166	834
Two or more	155	338	713	1210	1876	2031	1869

Figure 6.22 Prevalence of limiting and non-limiting conditions among people with conditions, by age group and condition number (1, 2 or more)

	16-44	45-64	65+
One condition	2160	2809	2000
Two conditions	1206	3086	3900

Figure 6.23 Prevalence of limiting and non-limiting conditions among people with conditions, by SIMD quintile and condition number (1, 2 or more)

	SIMD 5th least deprived quintile	4th	3rd	2nd	SIMD 1st most deprived quintile
One condition	1230	1665	1497	1276	1301
Two conditions	1092	1551	1745	1763	2041

Figure 6.24 Prevalence of living in owner-occupied housing by condition number (0, 1, 2 or more) and age group

	16-24	25-34	35-44	45-54	55-65	65-74	75+
No conditions	1975	2673	3061	2662	1725	1009	482
One	421	689	1047	1348	1451	1164	831
Two or more	155	338	712	1210	1871	2027	1867

Figure 6.25 Proportion of adults who were married or cohabiting, by condition number (0, 1, 2 or more) and age group

	16-24	25-34	35-44	45-54	55-65	65-74	75+
No conditions	1977	2673	3063	2671	1728	1009	488
One	421	690	1048	1352	1456	1166	834
Two or more	155	338	713	1210	1874	2031	1868

Figure 6.26 Kaplan-Meier plot of survival among adults aged 16-54, for the five long-term and limiting condition status groups (14.9 years' follow-up), SHeS 1998-SMR linked data

	Events	Censored	Total
No conditions	92	3469	3561
1 non-limiting condition	31	799	830
1 limiting condition	37	520	557
2 or more conditions, 0 limiting	13	155	168
2 or more conditions, at least 1 limiting	75	468	543

Figure 6.27 Kaplan-Meier plot of survival among adults aged 16-54, for the six long-term condition and Carstairs deprivation status groups (14.9 years' follow-up), SHeS 1998-SMR linked data

	Events	Censored	Total
No conditions, not deprived	63	2658	2721
No conditions, deprived	29	811	540
1 condition, not deprived	39	996	1035
1 condition, deprived	29	323	352
2 or more conditions, not deprived	49	401	450
2 or more conditions, deprived	39	222	261

Figure 6.28 Kaplan-Meier plot of survival among adults aged 16-54, for the six long-term condition and GHQ12 status groups (14.9 years' follow-up), SHeS 1998-SMR linked data

	Events	Censored	Total
No conditions, GHQ <4	78	3080	3158
No conditions, GHQ ≥4	14	368	382
1 condition, GHQ <4	45	1037	1082
1 condition, GHQ ≥4	23	270	293
2 or more conditions, GHQ <4	46	377	423
2 or more conditions, GHQ ≥4	41	240	281

Appendix I: Supplementary material for Chapter 6

Imputation

Method

Multiple imputation (MI) was carried out using SPSS v19 (IBM, 2010). Missing data occurs in a number of ways, with the literature (for example, Sterne et al. (2009)) distinguishing between the following situations:

- Missing completely at random (the missing and observed values have no systematic differences; a rare occurrence)
- Missing at random (differences in the observed data can account for systematic differences between missing and observed data)
- Missing not at random (differences between missing and observed data remain even if the observed data have been taken into account)

Little's MCAR test was applied to assess the assumption that the data missing from SWEMWBS was missing completely at random. This yielded a significant result ($p<0.001$), hence the data could not be considered to be missing completely at random. Tables 6.7 and 6.8 in Chapter 6 illustrate some of the factors associated with missing SWEMWBS data.

Strategies for handling missing data include complete case analyses, which was adopted for the majority of the analyses in Chapter 6, and is the predominant method used in most epidemiological studies with missing data (see, for example, Karahalios et al.'s 2012 review of cohort studies). However, the bias associated with complete case analyses, arising from the potential for people with missing data to be systematically different to those with complete data, resulted in this additional investigation of the data. An alternative method of handling missing data, weighting, can be used to adjust the results using what information is available about the people for whom all data are missing - the whole dataset uses non-response weights based on characteristics measured at the household level, and within households, using the age and sex of non-respondents. Imputation can also be used to assign plausible values for participants who did not complete certain items of interest, but who did take part in the rest of the survey. Various imputation mechanisms exist, with the simplest being to assign the mean value for the observed data to the missing cases, which overcomes the problem of loss of statistical power associated with missing data, but introduces distortion to the overall distribution of the data (Gelman and Hill, 2006). Eekhout et al. (2014) suggest that mean imputation results in considerable bias when more than 10% of cases are missing (SWEMWBS data was missing in just under 10% of cases). Furthermore, imputing methods that use a single step do not account for the uncertainty associated with the imputed values, and leads to an underestimation of the standard errors.

MI was the approach chosen to explore here. This overcomes the problem of underestimating standard errors by creating multiple datasets, each with their own set

of imputed values, and generating estimates based on pooling these multiple sources (which acknowledges the uncertainty associated with the single imputed estimates). As the SWEMWBS data were missing in around 10% of cases, 10 imputation datasets were created, following advice suggested in Allison (2012), though others suggest as many as 20-100 imputation datasets might be appropriate (Graham et al. 2007). As SWEMWBS is a composite score derived from 7 individual questions, the missing data could be imputed individually for each item, or overall for the total score. The latter approach was followed, largely for its simplicity, though some argue that this is in fact the more effective approach to take (Simons et al. 2015), while others (Eekhout et al. 2014) suggest otherwise.

SPSS can specify particular methods and constraints for the MI, in this case the full conditional specification was selected, which uses the Markov chain Monte Carlo method to impute values. As the values that SWEMWBS can take are constrained by the way the scale is constructed to always be integers that fall in the range 7-35, the same constraints were placed on the imputed values. The imputation model included the following variables: sex, age (in ten year groups), GHQ12 scores (continuous), highest educational qualification obtained, SIMD quintile, life satisfaction (as a continuous measure), and self-rated health.

Results

Table I1: Comparison of original and imputed values for prevalence of low wellbeing by condition number (0, 1, 2 or more) and age group (figures underlying Figures 6.20 & 6.21, Chapter 6)

% low wellbeing	16-24	25-34	35-44	45-54	55-64	65-74	75+
No conditions							
Original	11.3	7.8	6.6	6.6	4.6	3.3	6.7
Imputed	11.0	7.9	7.0	6.9	4.8	4.2	7.8
One condition							
Original	15.2	18.2	15.0	13.1	9.3	5.7	8.3
Imputed	15.1	19.0	15.7	13.4	9.8	6.8	10.2
Two or more conditions							
Original	26.7	32.6	37.3	30.9	22.9	13.2	18.9
Imputed	25.4	32.3	37.3	31.4	23.3	14.5	20.6

Table I2: Estimated odds ratios for low life satisfaction (score of 0-5), by condition status, with and without adjustment for age, sex and area deprivation

	OR	95% CI[a]
Condition status (p<0.001)		
Unadjusted		
One non-limiting condition (reference category)	1.0	
No conditions	0.8	0.7-0.9
One limiting condition	3.0	2.6-3.5
Two or more conditions, no reported limitations	1.1 [n.s.]	0.9-1.4
Two or more conditions, at least one limiting	5.4	4.8-6.2
Adjusted[b]		
One non-limiting condition (reference category)	1.0	
No conditions	0.8	0.7-0.9
One limiting condition	2.7	2.3-3.1
Two or more conditions, no reported limitations	1.2 [n.s.]	0.96-1.4
Two or more conditions, at least one limiting	5.1	4.5-5.8
Age group (p<0.001)		
16-24	0.4	0.3-0.4
25-34	0.7	0.6-0.8
35-44	0.8	0.7-0.9
45-54 (reference category)	1.0	
55-64	0.7	0.6-0.8
65-74	0.4	0.4-0.5
75+	0.4	0.3-0.4
SIMD quintile (p<0.001)		
5th least deprived (reference category)	1.0	
4th	1.2 [p=0.002]	1.1-1.4
3rd	1.6	1.4-1.9
2nd	1.9	1.6-2.1
1st most deprived	2.4	2.1-2.8
Partnership status (p<0.001)		
Married / cohabiting (reference category)	1.0	
No resident partner: single, never married	2.4	2.2-2.7
No resident partner: divorced / separated / widowed	2.3	2.1-2.6

[a]p value for all ORs <0.001, unless stated otherwise.

[b]Sex was also one of the adjustment factors, but it was non-significant (p=0.16).

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Full regression results (Tables 6.3 and 6.6)

Table I3: Unadjusted and adjusted odds ratios for low wellbeing by condition number – full results from Table 6.3 (Chapter 6)

SWEMWBS Score >1 SD below mean	Unadjusted OR	95% CI[a]	Adjusted OR[b]	95% CI[a]
Number of conditions (p<0.001)				
No conditions	0.6	0.5-0.6	0.5	0.4-0.6
One condition (reference category)	1.0			
Two	1.6	1.5-1.8	1.8	1.6-2.0
Three	2.4	2.1-2.7	2.8	2.4-3.2
Four	3.0	2.5-3.5	3.4	2.8-4.1
Five or more	4.3	3.6-5.1	5.2	4.3-6.2
Two or more	*2.2*	*2.0-2.5*	*2.4*	*2.2-2.7*
Sex (p=0.013)[c]				
Men (reference category)			1.0	
Women			1.1	1.02-1.2
Age group (p<0.001)				
16-24			1.1 [n.s.]	0.9-1.3
25-34			1.1 [n.s.]	1.0-1.3
35-44			1.1 [n.s.]	1.0-1.2
45-54 (reference category)			1.0	
55-64			0.7	0.6-0.8
65-74			0.3	0.3-0.4
75+			0.5	0.4-0.6
SIMD quintile (p<0.001)				
5th least deprived (reference category)			1.0	
4th			1.3	1.1-1.5
3rd			1.7	1.5-1.9
2nd			2.0	1.8-2.3
1st most deprived			2.5	2.2-2.9
Partnership status (p<0.001)				
Married / cohabiting (reference category)			1.0	
No resident partner: single, never married			1.6	1.5-1.8
No resident partner: divorced / separated / widowed			1.8	1.6-2.0

[a]p value for all ORs <0.001, unless stated otherwise.

[b]adjusted for sex, age, area deprivation & partnership status.

[c]OR estimates for adjustment factors are for the model with 0-5 or more conditions.

Table I4: Unadjusted and adjusted odds ratios for low wellbeing by limiting condition status – full results from Table 6.6 (Chapter 6)

SWEMWBS Score >1 SD below mean	Unadjusted OR	95% CI[a]	Adjusted OR[b]	95% CI[a]
Condition status (p<0.001)				
One non-limiting condition (reference category)	1.0		1.0	
No conditions	0.9	0.8-1.0	0.7	0.6-0.8
One limiting condition	2.5	2.1-2.9	2.1	1.8-2.5
Two or more conditions, no reported limitations	1.1	0.9-1.4 [n.s.]	1.3 [p=0.02]	1.04-1.6
Two or more conditions, at least one limiting	4.2	3.7-4.7	4.3	3.7-4.9
Sex (p=0.02)				
Men (reference category)			1.0	
Women			1.1	1.01-1.2
Age group (p<0.001)				
16-24			1.1 [n.s.]	0.9-1.3
25-34			1.1 [n.s.]	0.9-1.2
35-44			1.1 [n.s.]	0.9-1.2
45-54 (reference category)			1.0	
55-64			0.7	0.6-0.8
65-74			0.4	0.3-0.4
75+			0.5	0.4-0.6
SIMD quintile (p<0.001)				
5th least deprived (reference category)			1.0	
4th			1.2	1.1-1.4
3rd			1.7	1.4-1.9
2nd			2.0	1.7-2.3
1st most deprived			2.4	2.1-2.8
Partnership status (p<0.001)				
Married / cohabiting (reference category)			1.0	
No resident partner: single, never married			1.6	1.4-1.8
No resident partner: divorced / separated / widowed			1.7	1.6-1.9

[a]p value for all ORs <0.001, unless stated otherwise.

[b]adjusted for sex, age, area deprivation & partnership status.

Appendix J: Supplementary material for Chapter 7

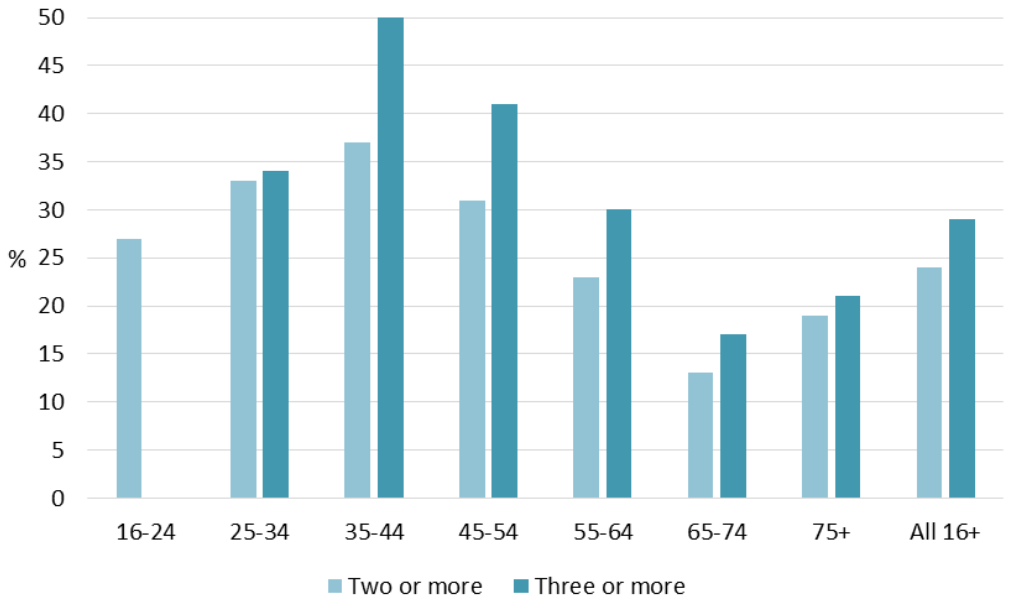
Table J1: Prevalence of reporting long-term conditions and other health problems, SHeS 2008-2011 and 2012-2013 compared.

	Any long-term condition	Any other health problem
Year	**%**	**%**
2008-2011	42.1	14.7
2012-2013	44.8	12.0
Sample size		
2008-2011	*28,772*	*28,765*
2012-2013	*9702*	*9706*

Table J2: Correspondence between unprompted and directly reported conditions, SHeS 2008-2011 and 2012-2013 compared.

	Proportion of those who mentioned a long-term condition, who also directly-reported a doctor diagnosis of it	Proportion of those with directly-reported doctor-diagnosed conditions, who also mentioned them as a long-term condition	Level of agreement (Kappa value)
2008-2011	**%**	**%**	
Hypertension	98	28	Moderate-poor (0.39)
Diabetes	97	73	Excellent (0.83)
2012-2013			
Hypertension	98	35	Moderate (0.47)
Diabetes	97	76	Excellent (0.84)

Figure J1: Prevalence of low wellbeing (>1 SD below mean) by age group and number of conditions (two or more and three or more compared)



Note: due to the small sample size (40) for people aged 16-24 with three or more conditions, figures for this group have not been presented. The sample size for the 25-34 age group with three or more conditions is only 88, so estimates should be treated with caution.